Social Capital in Breast Cancer Screening

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Abbreviations and Acronyms

ACS	American Cancer Society
BRCA1	Breast Cancer 1
BRCA2	Breast Cancer 2
BSE	Breast Self-Exam
CAD	Computer-Aided Detection
CBE	Clinical Breast Exam
CNB	Core Needle Biopsy
CT	Computed Tomography
DCIS	Ductal Carcinoma In Situ
FFDM	Full-Field Digital Mammography
FNAB	Fine Needle Aspiration Biopsy
FSU	Forward Strategy Unit
ICSN	International Cancer Screening Network
ILC	Invasive or Infiltrating Lobular Carcinoma
MMY	Mammography
MRI	Magnetic Resonance Imaging
OECD	Organisation for Economic Cooperation and Development
PET	Positron Emission Tomography
SES	Socioeconomic Status
SLN	Sentinel Lymph Node Biopsy
TNM	Tumor Node Metastasis Classification System
UICC	International Union Against Cancer
US	Ultrasound
WHO	World Health Organization
WVS	World Values Survey

1. INTRODUCTION

Many European nations have instituted publicly reimbursed breast cancer screening programs. Internationally, private opportunistic screening is also available in numerous countries. Opportunistic screening is screening "offered outside an organized screening program" (Canadian Cancer Society 2009). Previous and ongoing studies have evaluated participation and re-uptake rates in screening and the variables that influence these rates. Worldwide, many studies have also focused on socioeconomic predictors of breast cancer screening and their effect on the stage at diagnosis (Rosenberg et al. 2005). Fewer studies, however, have explored the concept of social capital in relation to screening. If social capital has a significant effect on screening rates and participation, this can prove useful for policy and programming decisions. *Norges Forskningsråd* (2005) has identified social capital as a potentially important factor for policymaking and problem solving efforts.

The intent of this paper is to examine social capital in screening programs in general and in breast cancer screening programs in Norway in particular. A questionnaire distributed in coordination with the Norwegian *Foreningen for Brystkreftopererte* was used to identify variables that affect mammography uptake, screening, and participation as well as the variables that influence the use of opportunistic screening and rehabilitation. The questionnaire was distributed to 3000 *Foreningen for Brystkreftopererte* members aged 40 to 69 who have been diagnosed with breast cancer. To define relevant variables, the questionnaire requested information about several topics, including demographic information, public and private screening, treatment, rehabilitation, breast reconstruction, use of follow-up services, social capital, health status, education, employment, and knowledge and opinions about genetic testing for breast cancer.

In Section 2 “Screening,” the paper begins by discussing screening in general and then explores breast cancer screening in particular in Section 3. Breast cancer epidemiology, staging and types, treatment, and rehabilitation issues are then discussed in Section 4. Afterwards, Section 5 of the paper addresses the concept of social capital in general terms and then in regard to screening and breast cancer screening. In Section 6 social inequality is briefly discussed. Section 7 “Data” provides an overview of the questionnaire responses

while Section 8 addresses the methods used in this study. Section 9 addresses the results and analysis, and conclusions are discussed in Section 10.

2. SCREENING: DEFINITION, PURPOSE, TERMS, AND IMPORTANT CONSIDERATIONS

Screening may be defined as "'the systematic application of a test or inquiry, to identify individuals at sufficient risk of a specific disorder to warrant further investigation or direct preventive action, among persons who have not sought medical attention on account of symptoms of that disorder"' (Jepson et al. 2000, p. vii). The goal of screening is to detect disease in the earliest stages in individuals who are at particular risk for the disease. Routine screening is intended to detect illnesses for which there may be no symptoms or apparent evidence of disease. After several years, properly implemented screening programs are expected to evidence a decrease in mortality (Hofvind, Geller, et al. 2007). According to Miller (1985), screening programs should exhibit several characteristics, including having screening tests that possess appropriate sensitivity, specificity, and validity. There are numerous terms and concepts that are relevant when designing or evaluating screening tests and screening programs. A true-positive test result is a positive test result for someone who actually has the disease being tested. A true-negative test result is a "normal or negative" test result for someone who does not have the disease being tested. A false-positive result is a positive or "abnormal" result for someone who does not have the disease while a false-negative test result is a normal or negative result for someone who has the disease (Yarbro, Goodman, & Frogge 2005). Sensitivity describes the "ability" of a test to identify people with disease. Low sensitivity will result in many false-negative test results, which will therefore lower the detection rate for cancers; if there is low sensitivity, there will be many people whose cancers remain undetected in the screening process. Specificity refers to the "ability" of a test to detect people who do not have the disease. While low sensitivity may lead to a problem of false-negative test results, low specificity may cause many false-positive test results in individuals who do not actually have the disease (p. 117).

It is also important to consider positive predictive value (PPV) and negative predictive value (NPV). The positive predictive value is the "proportion of positive tests that" reflect true-positive test results (Yarbro, Goodman, & Frogge 2005, p.117). The PPV is affected by the prevalence of a disease. Corner and Bailey (2001) provide the following example: "For example, a test with 99% sensitivity and 95% specificity would have a positive predictive value of 17% with a 1% prevalence, 29% with a 2% prevalence, and 51% with 5%

prevalence" (p. 55). The negative predictive value reflects "the proportion of negative tests that are" true-negative results (Yarbro, Goodman, & Frogge 2005, p.117). Another important term is validity. Validity is "the extent to which a test measurement or other device measures what it is intended to measure" (Anderson, Keith, Novak, & Elliot 2002, p. 1790). This may be particularly relevant when constructing evaluation criteria for screening programs.

According to Yarbro, Goodman, & Frogge (2005), if a screening program is to be implemented for a particular disease, "the disease should have a preclinical stage before symptoms become obvious" (p. 117). Mammography, for example, may identify breast cancer in the preclinical stage. Also, the screening test for the disease should be "acceptable to the individuals being screened" as well as "widely available and easily accessible" (p. 117). The screening program should be for an illness that is “common…and the cause of substantial mortality and/or morbidity” (Miller 1985, p. 10). In addition, the “natural history” of the illness “should be known” to assist in the development of appropriate screening guidelines (p. 11). A further consideration is that an “effective” treatment exists if illness is discovered during the screening process (p. 12). As previously mentioned, the screening test should also be acceptable to the relevant population; it should also be safe (p. 13). Safety considerations help to ensure that the screening test or process is not harmful to the population being screened or that the risk of harm is minimal compared to the expected benefits. X-ray mammography, for example, has been deemed to have an acceptable level of radiation exposure (Corner and Bailey 2001, p. 54; Humphrey et al. 2002, p. 194). Appropriately identifying the target population for a population screening program is also quite important; the target population should encompass those who are “known to have a high prevalence” for the illness (Miller 1985, p. 15). Methods for the evaluation of the screening program should also be available.

Holland, Stewart, & Masseria (2006) also discuss appropriate features for a screening program. Some of the features mentioned are identifying the target population and the individuals within that population who will be screened, encouraging those eligible for screening to attend screening, having “adequate premises, equipment and staff,” “an appropriate, satisfactory method of ensuring the maintenance of the best standards of the test(s),” and also “adequate and appropriate facilities” for diagnosis and treatment when required (p. 11). They also outline factors for the evaluation of screening tests, including simplicity, sensitivity, specificity, accuracy, cost, acceptability, and repeatability.

A report by Wilson & Jungner (1968) for the World Health Organization (WHO) also discusses screening criteria, including the criterion that "There should be an accepted treatment for patients with recognized disease." In a review of the criteria proposed by Wilson and Jungner (1968), Andermann (2008) et al. proposed a revised set of criteria. The criteria are as follows:

"• The screening programme should respond to a recognized need.
• The objectives of screening should be defined at the outset.
• There should be a defined target population.
• There should be scientific evidence of screening programme effectiveness.
• The programme should integrate education, testing, clinical services and programme management.
• There should be quality assurance, with mechanisms to minimize potential risks of screening.
• The programme should ensure informed choice, confidentiality and respect for autonomy.
• The programme should promote equity and access to screening for the entire target population.
• Programme evaluation should be planned from the outset.
• The overall benefits of screening should outweigh the harm."
Andermann et al. (2008)

There are several more terms that are relevant to cancer screening and cancer screening programs. The term "prevalent screening" or "prevalent screen" refers to a person's first screening. An interval cancer is a cancer found between "two consecutive screening rounds following a negative" screening (Vitak 1998, p. ix). A true interval cancer is an interval cancer that "even retrospectively" can not be "detected" in the person's previous screening session (p. xii). The screening interval is the time between "two consecutive screening rounds" (Vitak 1998, p. xi). In Norway, for example, there is a two-year screening interval for the public mammography screening program.

Other important terms include lead time, length time bias, and overdiagnosis (Vitak 1998, p. ix). Lead time is the time period between screen detection of cancer and the time it would have been discovered or diagnosed based on "symptoms and signs" in the absence of screening (p. ix). This is depicted in Figure 1. Length time bias refers to the concept that the "outcome [may] appear better in [the] screened group because more cancers with a good prognosis are detected" (Fletcher 2005, p. 153). This is related to the issue of overdiagnosis. Overdiagnosis refers to the fact that screening may find cancers that have "a good prognosis"

and would not have lead to difficulties for the patient (p. 160). It may also be defined as the "detection of lesions that would not have caused clinical symptoms or morbidity" (p. 237).

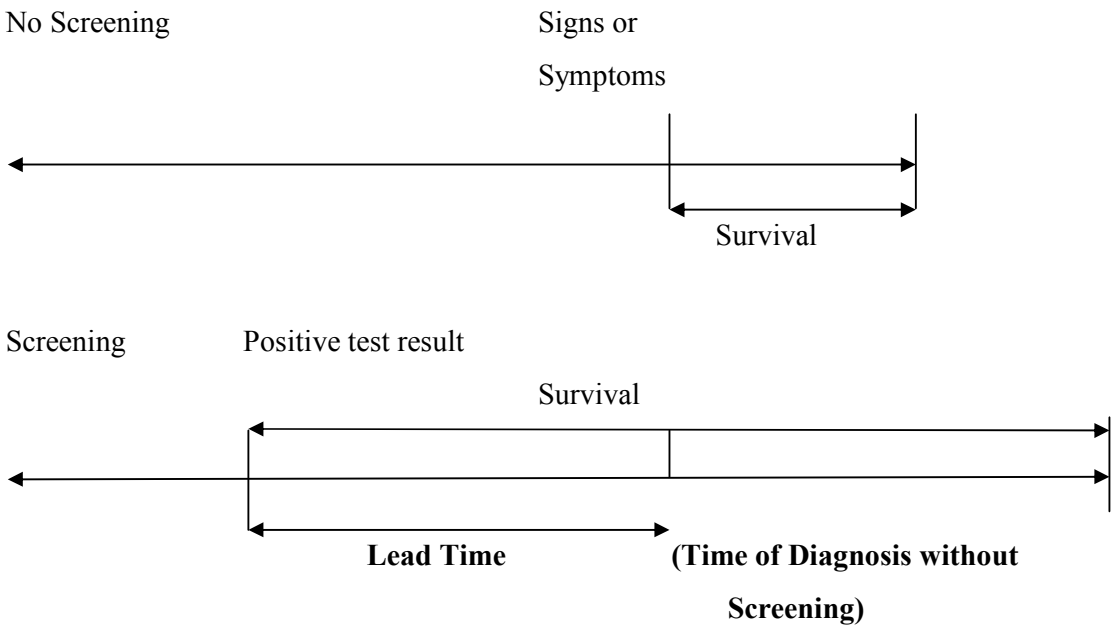


Figure 1. Lead Time [Similar to Figure 224.1 in Hoppe 1990 (p. 1023) and Figure 2 in Stanley 2001 (which was reprinted from Black & Welch 1997)]

Compliance is also quite important in screening. Compliance refers to "the extent to which patients follow medical advice" (Fletcher 2005, p.153). In that people who follow screening recommendations are following medical advice, they can be said to be exhibiting compliance. Other important terms include participation (or uptake) and re-attendance. Re-attendance may also be called re-uptake. In the context of mammography screening, participation rates measure the percentage of women in the recommended screening age who are actually being screened. In certain programs, such as the Norwegian Breast Cancer Screening Program, participation rates measure the percentage of women invited to be screened who attend screening. Re-attendance or re-uptake refers to later screenings by those who have previously attended screening. For example, if the recommendation is for breast cancer screening every two years from the age of 50, a woman who attends screening at age 50 is exhibiting compliance. She has participated in screening. However, if she never attends mammography screening again, this is a lack of re-attendance. If she does participate again in 2 years, this is an example of re-attendance or re-uptake. Compliance, participation, and re-attendance may

be affected by a variety of factors. These factors will be described and explored in more detail in the "Existing Literature" section in Section 3 "Breast Cancer Screening."

3. BREAST CANCER SCREENING

3.1 Screening Recommendations

Various countries and organizations have established guidelines for screening programs (Holland, Stewart, & Masseria 2006). The European Union Council, for example, includes breast cancer screening in its list of cancer screening recommendations; it recommends mammography screening every two to three years for women in the age range of 50 to 69 years (European Union Council 1999). However, this differs from recommendations in some countries, such as the United States, in which the recommendation is for mammography screening to commence at age 40 (ACS 2008). Though there is some variation in recommendations by various agencies and organizations, complete breast cancer screening recommendations in the US for the average-risk population include monthly breast self-examinations starting at age 20, "annual clinical breast examinations" for women aged 40 and over and at least every three years for women aged 20 to 49, and annual "mammography beginning at age 40 years" (Winchester et al. 2006, p. 272). However, "When an abnormality is detected on screening examination, additional diagnostic studies may include compression or magnification views, ultrasonography, and magnetic resonance imaging (MRI)" (Winchester et al. 2006, p. 272).

Internationally, there are differences in screening recommendations. As discussed earlier, regular breast self-exams and physical breast examinations by a healthcare provider, such as a gynecologist or general practitioner (family doctor), are also recommended in some countries as an adjunct to other screening methods (ACS 2008; Miller 1985). An overview of breast cancer screening in selected countries is provided in Table 1; the table does not include detailed clinical breast examination and breast self-examination recommendations for all countries or information about private screening options in all countries. Also, much of the data is based on information from a 1995 survey conducted by the International Cancer Screening Network (ICSN) and the resulting publication by Shapiro et al. (1998), so the information in Table 1 is not necessarily reflective of current policies and programming in the countries listed. In a literature search, a more recent comprehensive survey of international breast cancer screening practices was not found.

Table 1. Breast Cancer Screening Worldwide (Surveillance for the Average Risk Population)

Country	**Recommended Screening Ages**	**Screening Type**	**Screening Interval**	**Funding**
Norway[c]	50-69	MMY BSE	2 years	Public, PR*
Sweden[f]	40-74 (varies by county)	MMY	1.5 to 2 years	Public
United Kingdom[e]	50-70	MMY	3 years	Public
France[f]	50-69	MMY	2-3 years	Public
The Netherlands[f]	50-69	MMY	2 years	Public
Finland[f]	50-59	MMY	2 years	Public
Japan[f]	30 and over	CBE BSE	Yearly	Public
Australia[d,f]	50-69 (Available 40-49 and over 69)	MMY	2 years	Public
USA[a,b]	40 and over 20-25 20	MMY CBE BSE	Yearly Yearly (40 and above) to every three years (20-39) Monthly	Mostly Private, Public-Medicare/Medicaid Varies Not Relevant
Canada[f]	50-69 (varies by province)	MM CBE BSE	1-2 years	Public Public (in some provinces)

PR*-Private Screening is also available.
MMY (Mammography), BSE (Breast Self-Examination), CBE (Clinical Breast Examination)
Sources: (ACS 2009[a]; Sloan-Kettering 2009[b]; Kreftregisteret 2009[c]; Australian Government Department of Health and Ageing 2009[d]; UK NHS 2009[e]; Shapiro et al. 1998[f])

3.2 Breast Cancer Screening in Norway

The publicly-funded Breast Cancer Screening Program in Norway is described in detail by numerous sources (Hofvind, Geller, et al. 2007; Hofvind, Wang, & Thoresen 2003; Østerlie et al. 2008; Hofvind, Vacek, Skelly et al. 2008). The program was implemented nationwide over a period of years; this was preceded by a pilot program (Hofvind, Sørum, & Thoresen 2007). The timeline for the introduction of the public mammography screening program to various counties is detailed in Table 2; the information is from a chart that is available at the Kreftregisteret website (Kreftregisteret, 2009). In Norway, women are invited for screening biennially from the ages of 50 to 69. The "invitation" includes an appointment date and time, a brochure about breast cancer and breast cancer screening, and a questionnaire (Østerlie et al. 2008). The Norwegian Breast Cancer Screening Program meets the recommended levels of the European Guidelines for selected process indicators (Hofvind, Geller, et al. 2007; Perry et al. 2006). Private screening options are also available, and some women respond to advertisements for this opportunistic screening. This may expand the age range and frequency at which some women are screened beyond the age range and biennial screening of the public mammography screening program**.**

Table 2. Mammography Screening Introduction In Norway (By County)

County	**Time of Introduction**
Rogaland	November 20, 1995
Oslo	January 8, 1996
Hordaland	January 15, 1996
Akershus	February 12, 1996
Telemark	September 13, 1999
Agder Counties	November 1, 1999
Troms and Finnmark	May 22, 2000
Østfold	April 17, 2001
Nordland	May 17, 2001
Buskerud	September 10, 2001
Trøndelag Counties	September 17, 2001
Oppland	January 14, 2002
Møre og Romsdal	April 14, 2002
Sogn og Fjordane	February 3, 2003
Hedmark	August 25, 2003
Vestfold	February 2, 2004

Source: Kreftregisteret 2009--Based on a chart from the Kreftregisteret website

3.3 Mammography

Mammography meets the guidelines and suggestions for screening programs that were described in Section 2 “Screening.” Mammography may identify breast cancer in the preclinical stage. According to Strax (in Miller 1985), mammography is the “most reliable method for imaging breast lesions” (p. 141). Mammograms allow the detection of breast cancers that may not be discovered in physical examinations. It “is used to detect abnormalities and classify them as benign or malignant”; if the result is not clear or shows possible signs of disease, other testing and procedures, such as “supplementary views, ultrasound, magnification mammography, MRI, computer tomography, and nuclear medicine technique[s]” may be used (Alto et al. in Suri & Rangayyan 2006, p. 110). According to the American Cancer Society (ACS), most breast lumps are benign. Suspicious mammography results may be followed by additional mammograms, ultrasound, MRI, or biopsies. Biopsy may also be used “if these methods do not lead to a definite diagnosis but indicate a high suspicion for malignancy, and conformation of malignancy is required” (Alto et al. in Suri & Rangayyan 2006, p. 110). A biopsy may be a fine needle aspiration biopsy (FNAB) or a core needle biopsy (CNB) (Hofvind, Geller et al. 2007; Vimpeli et al. 2008). FNAB is “a quick, inexpensive technique to assist in several areas of breast care management” (Fine in Winchester et al. 2006, p. 185). It can help differentiate “benign from malignant solid breast masses” (Fine in Winchester et al. 2006, p. 185).

Numerous randomized controlled trials and demonstration projects have demonstrated the efficacy of mammography for the detection of breast cancer lesions (Greenwald et al. in Miller 1985, p. 30; Miller 1985, p. 330-336). There are, of course, instances in which false positives and false negatives occur; this may be due to reader error or inexperience or due to structural features that can not be adequately distinguished from breast cancer via mammography. An article by Hofvind, Thoresen, and Tretli (2004) estimated a false-positive recall rate using data from three mammography screening rounds in selected counties in Norway (p. 1501). The results of 83,416 women aged 50 to 51 who had been screened in all 3 rounds were used in the estimation. Hofvind, Thoresen, and Tretli (2004) found a "cumulative risk of 20.8% for a false-positive recall during a screening period of 2 decades" (p. 1501). The authors emphasized that "it is important to communicate the existence and extent of this risk to the target group" but "the cumulative risk seemed to be acceptable in the Norwegian Breast Cancer Screening Program" (p. 1501). The Norwegian Breast Cancer

Screening Program utilizes independent double-reading of mammograms to help reduce the risk of false-positives and false-negatives. Also, when a woman has been screened previously, comparison to previous or baseline mammograms can be useful. As Hofvind, Thoresen, and Tretli (2004) noted, "a previous screening mammogram decreases the false-positive recall rate" (p. 1506).

The occurrence of false-positives and false-negatives also relates to the strengths and limitations of mammography screening. According to Guo, Suri, and Sivaramakrishna (in Suri and Rangayyan 2006), mammography screening has a sensitivity of around 70% and a positive predictive value of 30% and in clinical trials has also evidenced a 25% to 30% breast cancer mortality reduction in women aged 50 to 70 (p. 430). They caution that mammography has "limited specificity and sensitivity" and misses approximately 10% of cancers, "especially those in dense breasts" (p. 430). They also mention that about two-thirds of those cancers are "detected retrospectively by radiologists" (p. 430). Also, approximately two-thirds "of lesions sent to biopsy turn out to be benign" (p. 430). The authors state that these issues have lead to "the investigation of alternative imaging modalities such as ultrasound, MRI, computer tomography (CT), and PET (positron emission tomography), etc. for the detection and diagnosis of breast cancer" (Guo, Suri, and Sivaramakrishna in Suri and Rangayyan 2006, p. 430).

Randomized controlled trials have also shown that early detection of breast cancer can improve health outcomes (Hofvind, Sørum, & Thoresen 2007). As mentioned previously, the most common method for breast cancer screening worldwide is mammography. According to Hagen (2007), the "triple diagnostic model" of "mammography, clinical examination and fine needle aspiration and/or core biopsy" has become the "gold standard for investigation of breast tumors. Hagen reports a "diagnostic accuracy" of greater than 99% when the three methods are combined (Hermansen et al. 1987 as cited in Hagen 2007). Mammography "has shown clear evidence of mortality reduction" (Kopans in Winchester et al. 2006, p. 116). According to Chen, Wardley, and Skarin (2007), "the widespread use of routine mammography has led to increased detection of early primary lesions, a factor that has contributed to a significant decrease in mortality" (Chen, Wardley, and Skarin 2007, p. 23). The Health Insurance Plan study and the Swedish Two-County trial "had sufficient numbers to show statistically significant mortality reduction of 20 to 30% for women invited to be screened" (Kopans in Winchester et al. 2006, p. 116). Studies have demonstrated that

"Screening mammography reduces breast cancer mortality in women older than 50 years of age" (Arun and Kuerer in Winchester et al. 2006, p. 97). Also, double reading of mammograms "has been shown to increase the number of cancers detected" (Kopans in Winchester et al., p. 117).

There is some question about appropriate screening ages and appropriate screening intervals. Sener and Smith (2006) note that "...there were higher incidences of interval cancers in younger than older women and in women with increased versus decreased mammographic density….[This has] led to the conclusion that, while screening at a 1-year interval is likely more beneficial than longer intervals for all women, there clearly is more benefit to annual screening in younger than older women" (Sener and Smith in Winchester et al. 2006, p. 113). A Kunnskapssenteret report (Bjørndal and Forsetlund 2007) found that women in their 40s who participate in a ten-year screening program have a bit lower risk of dying of breast cancer compared to women who do not engage in such a program.

Mammography remains an evolving technology. Digital mammography in which the image is "recorded, viewed by the doctor, and stored" digitally is "under development" and is being used in many countries, including Norway (Suri and Rangayyan 2006, p. 432). Initial studies and results suggest that "the digital mammogram is at least as accurate as the x-ray mammogram" while "Full-field digital mammography (FFDM) offers a field of view large enough to image the entire breast…" (Suri and Rangayyan 2006, p. 433 & p.432). According to Sarvazyan, Egorov, Son, and Kaufman (2008), "the overall diagnostic accuracy in a large-scaled[sic] clinical study was found of[sic] 0.78 ± 0.02 for digital mammography and of[sic] 0.74 ± 0.02 for film mammography" (p. 91); they concluded, however, that this improvement was not significant. Though results of this and other studies have varied, the indication based on the current literature is that digital mammography may improve the detection capabilities of mammography.

It should be noted that the efficacy of mammography and other screening techniques in detecting breast cancers is also affected by the type of equipment used (ex. analog versus digital) and by the experience of the examiner (Hofvind, Geller, Vacek et al. 2007; Hofvind, Vacek, Skelly, et al. 2008). Imaging and diagnostic technologies continue to evolve. Some women have observed that the mammography process is painful (Hofvind, Wang, & Thoresen 2003). Newer technologies may help eliminate this potential barrier to screening.

3.4 Magnetic Resonance Imaging (MRI) and Computed tomography (CT)

Mammography is the most commonly used method for breast cancer screening in the general population. However, other methods may also be used alone or in conjunction with mammography, particularly for women who may be at higher risk or who may not be good candidates for mammography. As previously mentioned, other methods for breast cancer screening may include MRI in conjunction with mammography for women at higher risk (ACS 2008). Different types of breast MRI, such as contrast-enhanced breast MRI, are available (Wu and Markey in Suri and Rangayyan 2006, p. 741). An overview of MRI is provided by Suri and Rangayyan (2006):

> "MRI uses magnetization and radiowaves instead of x rays to produce very detailed, cross-sectional images. The most useful MRI examinations for breast imaging use a contrast material that is injected into a small vein in the arm before or during the examination…Breast MRI is effective for all classes of women, has the ability to image dense breasts, and can give dynamic information about angiogenesis. Although MRI can detect some conditions not seen on the mammogram, it is less accurate than a routine mammogram in determining which of the abnormal areas are cancer and which are not" (Suri and Rangayyan 2006, p 430-431).

According to Schnall (2006), "In 1989…(it was) demonstrated that MRI was capable of imaging mammography occult breast cancers"(Schnall in Winchester et al. 2006, p. 162). However, studies of breast MRI have reported varying sensitivity and specificity (p.166-168). According to Hylton (2005), "Because of its high sensitivity and effectiveness in dense breast tissue, MRI can be a valuable addition to the diagnostic work up of a patient with a breast abnormality or biopsy-proven cancer. The major limitation of breast MRI is the low-to-moderate specificity, which in combination with high sensitivity can lead to unnecessary biopsy, patient anxiety, and cost" (Hylton in Morris and Liberman, 2005, p. 7). Currently, studies indicate that MRI should not be used for "total population screening" but that it may be more "feasible" for higher risk individuals (Schnall in Winchester et al. 2006, p. 173). According to Schnall, "MRI should not be used as a screening test on its own, but in combination with mammography" (Schnall in Winchester et al. 2006, p. 173).

However, current evidence has demonstrated "contrast-enhanced MRI to be effective for early detection of cancer in high-risk women, and superior to mammography for identifying and demonstrating the extent of diffuse and multifocal breast cancer" (Hylton in Morris and Liberman, 2005, p. 7). In fact, "The sensitivity of MRI to breast carcinoma, particularly in

dense breast tissue, has led to the emerging role of MRI in breast cancer screening for women identified to be at high risk" (Hylton in Morris and Liberman, 2005, p. 7). Also, "The high staging accuracy of breast MRI has led to its use for assessing tumor response to neoadjuvant chemotherapy" (Hylton in Morris and Liberman, 2005, p. 7). Breast MRI has "a high sensitivity and a moderate specificity in detecting breast cancer" and "…it has been shown that standard mammography misses 10 to 30% of cancers that are visible using breast MR" (Meinel and Reinhardt in Suri and Rangayyan 2006, p. 792). This agrees with the figures reported by Wu and Markey (2006). According to Wu and Markey (2006), 10% to 30% of "breast cancers are not detected on mammography and the positive predictive value of mammography is less than 35%." (Wu and Markey in Suri and Rangayyan 2006, p. 740). Therefore, it is helpful to use other imaging techniques in addition to mammography.

CT scanning is sometimes used, but "The use of CT has been limited as a diagnostic tool of breast abnormalities because of radiation hazard and image quality"; therefore, "CT is preferred in systemic staging of breast cancer patients" (Suri and Rangayyan 2006, p. 431).

3.5 Ultrasound (US)

As previously mentioned, mammography is the most common method for breast cancer screening and is considered the "gold standard" for breast cancer screening (Peart, 2005, p. xi). However, ultrasound may also be used to investigate breast cancer and other abnormalities. Ultrasonography may be particularly useful in combination with mammography in certain cases, such as the presence of dense breast tissue, investigation of a palpable lump, or for "surveillance of high-risk women" (Hagen 2007, p. 9). According to Suri and Rangayyan (2006), "The most widely used adjunctive modality for breast imaging is ultrasound…Ultrasound is particularly valuable for…examining younger women with dense breasts" (Suri and Rangayyan 2006, p. 740). Also, "Ultrasound has become a valuable tool to use with mammograms because it is widely available and less expensive than other options. Breast ultrasound is used to target a specific area of concern found by the mammogram. It is a widely accepted adjunct to mammography in patients with palpable masses or symptomatic breast disease. It is well established that breast ultrasound can distinguish solid from cystic masses with an accuracy approaching 100%, and can detect lesions that are not mammographically visible'"(Suri and Rangayyan 2006, p. 430-431; Fornage in Winchester et al. 2006, p. 137). However, it does have limitations. According to Fornage (in Winchester et

al. 2006), "As a rule, sonography cannot depict isolated microcalcifications that would indicate the presence of an early intraductal carcinoma; these remain the domain of mammography" (p. 137).

It does, however, have positive features. Fornage states that "…with the use of state-of the-art high-resolution ultrasound transducers, masses –cystic or solid, large or small—are reliably identified, and ultrasound can now play a significant role in the diagnosis and management of breast masses, in general, and of breast cancer, in particular" (Fornage in Winchester et al. 2006, p. 137). It is, of course, important that the examiner be experienced and properly trained. Also, Fornage explains that "The concordance between sonographic and mammographic findings must be a priority for the sonologist" (p 139). Though ultrasound is not recommended for use without other screening methods, it does have marked ability to detect cancers. Fornage even mentions that "Carcinomas, even those less than 1 cm in diameter, are routinely identified on US with the use of state-of-the-art sonographic equipment" (p. 139).

Ultrasound may also be useful in staging breast cancer (Fornage in Winchester et al. 2006, p. 147). In addition, ultrasound can be used in ultrasound-guided fine needle aspiration biopsy (FNAB) of "lymph node-bearing areas" (p. 159). Ultrasound "differentiates cystic from solid masses…[and] also aids in discriminating between benign and malignant solid masses" (p. 159). Ultrasound "can detect nonpalpable carcinomas missed by mammography…[but] it cannot replace mammography for routine cancer screening as it cannot demonstrate microcalcifications and its success is highly operator dependent." (p. 159). However, as previously mentioned, ultrasound may be useful in examinations for particular categories of women. "Dense breasts…may represent a real challenge" during detection by mammography (Tot in Suri and Rangayyan, p. 19). Therefore, MRI or ultrasound "are often needed for tumor detection" (Tot in Suri & Rangayyan 2006, p. 19-20).

3.6 Advances in Technology

Newer technologies are being evaluated to increase the efficacy of screening. According to Suri et al. (2006), computer-aided detection (CAD) is being evaluated for use with a variety of breast screening and diagnosis tools, including x-ray mammography, MRI, breast ultrasound, and PET (Suri et al., p. 903-943). Computer-aided detection (CAD), "automated

screening systems that localize suspicious regions in an image for a radiologist to consider," are being evaluated to "improve sensitivity," "such as to detect subtle lesions in mammography that might otherwise be missed by the radiologist" (Lo et al. in Suri and Rangayyan 2006, p. 872).

3.7 Existing Literature on Breast Cancer Screening

Attendance at breast cancer screening may be affected by a variety of factors. As Miller (1985) notes, various cultural factors may decrease a woman's likelihood of attending breast cancer screening. Inappropriate understanding of risk as well as economic factors in some countries may have an impact on screening rates (Miller 1985). Attendance rates for screening in Norway are relatively high with a 77% attendance rate for all screening rounds and a 76% attendance rate for the last completed round of screening (Kreftregisteret 2009). Studies in Norway have examined factors affecting breast cancer screening and re-attendance. Trust, gratitude, and convenience were considered "more important factors" than "benefits, harms, and risks" when women in the population studied decided whether or not to attend screening (Østerlie et al. 2008). Glaeser et al. (2000) mention trust and trustworthiness as "two key components of social capital" (p. 811). It should also be noted that some women perceived their invitation to screen with the included appointment date and time as a foregone conclusion; it was already decided because they had an appointment time. The effect of the pre-scheduled appointment may be described as a "triggering effect" (Østerlie et al. 2008, p. 4). Study results also indicated that the "opt-out" nature of the Norwegian Breast Cancer Screening Program may overcome some barriers to screening, such as procrastination and the "threshold mile," while also potentially impairing a patient's ethical right to informed choice. The study also notes that women who attend the regular screening program only pay a small fee while those who choose opportunistic screening assume the financial costs of attendance (Østerlie et al. 2008). Previous screening results and "experienced pain" were "related" to re-attendance; however, experienced pain was not a "significant predictor of re-attendance" (Hofvind, Wang, & Thoresen 2003). In the model used, intention to re-attend screening was the only variable that was found significant upon multiple logistic regression (Hofvind, Wang, & Thoresen 2003).

In studies, socioeconomic status has been shown to have an impact on screening patterns. In Taiwan, Lin (2008) found that participation in breast and cervical cancer screening was

related to age, marital status, income level, education, and health status. Lower socioeconomic status was related to not attending screening even when screening was free of charge. Healthy behaviors, such as exercising, also appeared to have "a positive effect on the uptake of screening" (Lin 2008). A study of screening in Spain found that the likelihood of participating in opportunistic mammography screening was positively related to age, educational level, and having voluntary private health insurance. Canada has a universal healthcare system. Nevertheless, in an older study, Katz and Hofer (1994) demonstrated that screening for breast and cervical cancer in Canada was affected by income (Katz and Hofer 1994). Also, college graduates had a higher rate of screening than those with "less than a high school degree" (p. 530).

In a study of the Dutch national breast cancer screening program, Lechner, de Vries, and Offermans (1997) found that "past breast cancer screening participation was strongly associated with positive determinants toward future screening participation, with the positive intention to participate in the next screening, and with the actual repeated participation in the second screening" (p. 473). In a health technology assessment, Jepson et al. (2000) performed a systematic review to identify variables that affect screening participation. They also tried to determine the "effectiveness of methods used to increase uptake" (p. vii). Most of the studies used in the review were from Canada or the United States. In their systematic review, Jepson et al. (2000) found that the following variables have a positive effect on participation in mammography screening: previous participation in mammography screening, “intention to attend,” having health insurance, or “receiv[ing] a recommendation to attend by their general practitioner” (p. viii). Age was also an important factor. The following methods were found to increase participation rates: “invitation appointments, letters (less effective for mammography) and telephone calls; telephone counselling; and removal of financial barriers (e.g. transport and postage costs)” (p. viii). The authors also mention that the following interventions may be effective: “educational home visits; opportunistic screening; multicomponent community interventions; simpler procedures; combination of different components aimed at individuals; reminders for non-attenders (for mammography only); and invitation follow-up prompts” (p. viii). Though their conclusions do not translate directly into the Norwegian setting, Doescher and Jackson (2008) found that women living in rural areas in the US were less likely to attend mammography screening than women living in more urban areas (p. 3). They suggested that differences may be in part explained by "greater distances to medical facilities and less accessibility of services" (p. 3).

The work of Grossman (Grossman 1999; Grossman in Culyer and Newhouse 2000) is also relevant to discussions of healthcare and screening. Grossman describes and elaborates on a human capital model. In this model he "views health as a durable capital stock that yields an output of healthy time" (Grossman in Culyer and Newhouse 2000, p. 348). He sets the parameters that "Individuals inherit an initial amount of this stock that depreciates with age and can be increased by investment" (p. 348). There are factors and variables that may influence human capital. He states that "I focus on education or years of formal schooling completed as the most important determinant of the stock of human capital" (Grossman in Culyer and Newhouse 2000, p. 373). According to McGuire, Henderson, and Mooney (2005), Grossman "has tended to concentrate upon the investment demand for health" (p. 106). In fact, Grossman postulated that education is related to an individual's willingness to invest in health. The thought is that investing in health may incur costs now but it leads to a reduction in costs later due to better health (Grossman in Culyer and Newhouse 2000). In the context of screening, this may support the hypothesis that more years of education increases a person's probability of participating in screening. Participation in screening may be viewed as an investment in health.

Folland (2006) also writes about variables that may impact healthcare behaviors and screening. Though social capital is discussed in detail in Section 5, Folland's treatment of social capital in the context of health risks will be mentioned in this section in relation to screening. Folland postulates that "more extensive" relationships increase a person's social capital (p. 159). This, in turn, leads to a change in the person's risk behaviors. According to Folland (2006), "when he marries, has children, acquires friends, or experiences a more socially active community," a person "chooses lower risks and thus better health" (p. 169). In regard to marriage, for example, Folland suggests that within the context of the marriage or relationship "the decision maker…[is] motivated to preserve his social capital and thus himself so as to enjoy it" and concludes that "his health is thus improved by his avoiding health risky behaviors" (p. 160). Extended to screening, this may lead to the hypothesis that increases in social capital, such as marriage, increase a person's likelihood of participating in screening.

4. OVERVIEW OF BREAST CANCER, BREAST CANCER TREATMENT, AND REHABILITATION

According to Kumle (2008), Weedon-Fekjær (2007), and Guo, Suri, and Sivaramakrishna (in Suri and Rangayyan 2006), breast cancer is the most common cancer among women worldwide with an incidence of around one million each year. "About ten percent of women are confronted with breast cancer in their lives" (Guo, Suri, and Sivaramakrishna in Suri and Rangayyan 2006, p. 430). In Norway, there were 2673 new cases of breast cancer in 2006, making breast cancer the most common cancer diagnosis for women in Norway (Larsen et al. 2007). According to Weedon-Fekjær (2007), "Norwegian women today have an estimated breast cancer lifetime risk of 10.8%, and breast cancer accounts for 3.3% of the deaths among Norwegian women" (p. 8). Rovere, Warren, and Benson (2006) report that "Almost half a million women die of the disease [breast cancer] annually worldwide" (p. xi). They also state that breast cancer is "predominantly a disease of post-menopausal women"; however, "almost one-third of cases occur in women under 50 years of age and it represents a major cause of death in the age group 40-50 years" (p. xi).

Weedon-Fekjær (2007) reports "breast cancer incidence increases in nearly all countries"; Weedon-Fekjær adds that "the disease has one of the youngest median age at diagnosis of the most common cancers" (Weedon-Fekjær 2007, p. 7). According to the American Cancer Society (ACS), the five year-relative survival rate for breast cancer ranges from 100% for cancers at Stage 0 or 1 at diagnosis to 86% for Stage II and reduces to 20% for Stage IV breast cancers ("Detailed Guide: Breast Cancer," ACS 2008). Early detection is therefore vitally important.

4.1 Risk Factors and Breast Cancer Symptoms

According to Humphrey et al. (2002), over half of breast cancers "occur in women without known major predictors" (p. 181). However, identified risk factors for breast cancer include gender, age, and gene mutations. Less than one percent of breast cancers "occur in men" (Anderson, Keith, Novak, & Elliot 2002, p. 237). Women above the age of 55 have the highest incidence of invasive breast cancers. Five to ten percent of breast cancers may be attributed to mutations in the BRCA1 (breast cancer 1), BRCA2 (breast cancer 2), or other genes (Ford et al. 1998, Easton 1999, & Peto et al. 1999 as cited in Hagen 2007). BRCA1,

BRCA2, CHEK2, ATM, TP53, and PTEN "confer increased susceptibility to breast cancer" (Walker and Eeles in Isaacs & Rebbeck 2008). "Inherited alterations in the genes called BRCA1 and BRCA2 are involved in many cases of hereditary breast and ovarian cancer" (NCI, 2002). BRCA1 and BRCA2 "encode a tumor suppressor gene in which mutations can lead to breast and ovarian cancer (Miki et al. 1994 & Wooster et al. 1994 as cited in Hagen 2007, p. 8). "A healthy BRCA1 gene produces a protein that protects against unwanted cell growth…When the gene is defective, it produces a faulty protein that is unable to prevent proliferation of abnormal cells as they evolve into potentially deadly breast cancer" (Anderson, Keith, Novak, & Elliot 2002, p. 236). "Women with mutations in these genes (BRCA-1 and BRCA-2) have an approximate 50 to 80% lifetime risk of developing cancer" (p. 96). Risk factors may vary for those with a genetic risk for breast cancer. "Early first pregnancy is not protective in BRCA1 or BRCA2 mutation carriers" (p. 96). Almost all hereditary cases of breast and ovarian cancers in Norway are linked to BRCA1 and BRCA2 genetic mutations; "approximately seventy percent of the BRCA1 mutation carriers in Norway have one of four founder mutations" (Moller at al. 2001 as cited in Hagen 2007, p.9). According to Hagen (2007), "BRCA1 mutation carriers in Norway have previously been offered annual mammography with optional ultrasound, and clinical breast examination (CBE)" (p. 60). However, breast MRI may prove to be a better "surveillance tool" for "BRCA1 associated breast cancers" in terms of mortality reduction (Hagen 2007, p. 60). Though genetic testing for some gene mutations is available, it is not routinely recommended in Norway.

There are also other risk factors for the development of breast cancer. Earlier age at menarche (younger than 12), later age at menopause (older than 55), and long-term use of certain kinds of hormone replace therapy (HRT) are also thought to contribute to an increased risk of breast cancer (Eddy 1980; ACS 2008). This is due to "prolonged estrogen exposure"; as Winchester et al. (2006) summarize, "Prolonged estrogen exposure, such as early menarche, late menopause, nulliparity, and late age at first pregnancy are associated with increased risk of breast cancer" (Winchester et al. 2006, p. 96). Additional risk factors are a family history of breast cancer, a previous breast cancer diagnosis, dense breast tissue, and some benign breast lesions. Hypertension may also increase the risk of breast cancer (Anderson, Keith, Novak, & Elliot 2002). There are several other risk factors that have been identified or indicated as having the potential to increase breast cancer risk. Some lifestyle factors have also been suggested as risk factors for developing breast cancer ("Detailed

Guide: Breast Cancer," ACS 2008). More detailed information on risk factors is available from the following sources: Winchester et al. 2006, Roses 2005, ACS 2008, and Finkel 2005.

According to Anderson, Keith, Novak, and Elliot (2002), "Tumors are more common in the left than in the right breast and in the upper and outer quadrant than in the other quadrants" (Anderson, Keith, Novak, & Elliot 2002, p. 237). Early breast cancer symptoms may be discovered by breast self-examination; these symptoms "include a small painless lump, thick or dimpled skin, or nipple retractions" (p. 237). As the cancer advances, symptoms may include "nipple discharge, pain, ulceration, and enlarged axillary glands" (Anderson, Keith, Novak, & Elliot 2002, p. 237). The axillary area is the area under the arm commonly referred to as the "armpit."

4.2 Staging of breast cancer

According to Winchester and Kennedy (in Winchester et al. 2006), "The vast majority of breast cancers diagnosed today are early stage. The use of routine screening mammography and increased breast cancer awareness are primarily responsible for the trend towards earlier diagnosis" (Winchester and Kennedy in Winchester et al. 2006, p. 272). "Breast cancer is most effectively treated when detected at an early stage, and the survival probability of the patient is dependent on the tumor size at detection time. The larger the tumor size, the larger the probability for the presence of metastases in vital organs. Early detection of the tumor is critical for a good prognosis" (Guo, Suri, and Sivaramakrishna in Suri and Rangayyan 2006, p.430). According to Eddy (1980), breast cancer can metastasize in three major ways; these are by growing into surrounding tissues, entering the circulatory system and thereby gaining access to other organs, or by using the lymphatic system to metastasize to the lymph nodes. "The current most commonly used staging classification [for breast cancer] is that provided by the American Joint Committee on Cancer" (Nurko, Broadwater, & Edwards in Winchester et al. 2006, p. 302). The International Union Against Cancer (UICC) also works with the TNM classification system (UICC 2009).

The Tumor Node Metastasis (TNM) System is also in use for other cancers. The following is a basic description of the system and does not include all the details of the system in regard to the staging of breast cancers. T describes the tumor size and the extent of growth of the tumor. N describes the progression of the cancer to lymph nodes. M describes the metastasis

of the cancer to other parts of the body (ACS 2008; Nurko, Broadwater, & Edwards in Winchester et al. 2006, p. 302). The letters T, N, and M are modified by letters and numbers that provide information about the progression of the breast cancer. "X" may be used if one of the three characteristics can not be evaluated. If it can be evaluated, the T may be described by "is" or by a number from 0 to 4. T0 indicates that there is "no evidence of primary tumor" while Tis indicates carcinoma in situ; the “is” in the designation “Tis” indicates carcinoma in situ. T1 to T3 indicate the size of the tumor while a "T4" "includes inflammatory breast cancer" and indicates a tumor of any size that is "growing into the chest wall or skin." N may be modified by the numbers 0 to 3. N0 means that the cancer has not metastasized to "nearby" lymph nodes. N1 through N3 are used to describe how many lymph nodes have been affected by the cancer while N3 may also indicate specified conditions, such as metastasis to lymph nodes below the clavicle. M may be 0 or 1. "M0" indicates that the cancer has not metastasized to distant areas while "M1" indicates it has metastasized to "distant organs" (ACS 2008).

After the T, N, and M categories are determined, the type of cancer is classified based on stage grouping. Stages range from 0 to IV. Non-invasive cancers (Tis, N0, M0) are Stage 0; this includes ductal carcinoma in situ (DCIS). In Stage I (T1, N0, M0), the tumor size is 2 cm or less across, and the cancer has not metastasized to the lymph nodes or other parts of the body. In Stage IIA (includes T0, N1, M0 as well as T1, N1, M0 and T2, N0, M0), a variety of situations is possible. However, the cancer has spread to a few lymph nodes but has not metastasized to "distant sites." In Stage IIB (includes T2, N1, M0 and T3, N0, M0), the cancer has not metastasized to distant organs. A tumor of at least 2 cm is present and the cancer has metastasized to the lymph nodes or the tumor is greater than 5 cm but has not "grow[n] into the chest wall or skin" or metastasized to the lymph nodes. In Stage IIIA (includes T0-2, N2, M0 and T3, N1-2, M0), the cancer has not metastasized to distant organs but has spread to certain lymph nodes. In Stage IIIB (includes T4, N0-2, M0), the cancer has "grown into the chest wall or skin" and may or may not have metastasized to the lymph nodes. However, it has not metastasized to distant organs. The ACS (2008) notes that inflammatory breast cancer is considered Stage IIIB if it has not metastasized to distant lymph nodes or sites. If it has metastasized to distant lymph nodes or sites, it is considered Stage IV. In Stage IIIC (includes T0-4, N3, M0), the cancer has not metastasized to distant organs but has spread to certain lymph nodes. In Stage IV (includes T0-4, N0-3, M1), the cancer has

metastasized to distant organs or distant lymph nodes and may or may not have affected local lymph nodes (ACS 2008).

According to Nurko, Broadwater, and Edwards (2006), “In the absence of distant metastasis, axillary lymph node status is the most accurate predictor of survival” (p. 302). Axillary lymph nodes are lymph nodes that are located under the arm in the armpit (or axillary) region. “Axillary lymph node staging for breast cancer requires a clinical and pathologic assessment of the presence and extent of breast cancer in the regional lymph nodes” (Nurko, Broadwater, & Edwards in Winchester et al. 2006, p. 302). They describe axillary lymph node staging as “a vital prerequisite to prescribing adjuvant hormonal therapy, cytotoxic drug, irradiation, and surgical therapy to achieve the therapeutic goals of local, regional, and systemic disease control” (p. 302). However, there are important disadvantages and effects of the use of axillary dissection. They note that “Axillary dissection for nodal staging has significant morbidity. The likelihood of post-operative lymphedema correlates with the extent of surgery. Lymphedema also represents the operative complication most likely to cause permanent disability with chronic pain and is often associated with recurrent episodes of cellulitis. Other complications associated with axillary lymph node dissection include postoperative seromas, decreased range of shoulder motion, and thrombophlebitis” (Nurko, Broadwater, & Edwards in Winchester et al. 2006, p. 303). Cellulitis is "an acute inflammation of the connective tissue of the skin, caused by infection with staphylococcus, streptococcus or other bacteria" (Medline Plus 2006). A seroma is "a build-up of clear bodily fluids in a place on your body where tissue has been removed by surgery" (Breastcancer.org 2008). Thrombophlebitis is "swelling (inflammation) of a vein caused by a blood clot" (Medline Plus 2008). These effects have long-term consequences, including quality of life effects, for women who undergo axillary lymph node dissection.

4.3 Types of breast cancer

There are numerous types of breast cancers. This paper will not discuss every type of breast cancer. However, it is important to note that both the stage and type of breast cancer are important in determining treatment and therefore rehabilitation options. Some breast cancers may be the result of several types of cancer; the term “mixed tumors” is sometimes used to describe them. According to the ACS, ductal carcinoma in situ (DCIS) or intraductal carcinoma is the most common non-invasive breast cancer. In this stage, the cancer is

contained in the ducts of the breast and has not entered the "surrounding breast tissue" (ACS 2008). DCIS is considered an early-stage breast cancer and has a high cure rate (ACS 2008). “Ductal carcinoma in situ (DCIS) of the breast is a proliferation of malignant cells within the lumen of the mammary duct…DCIS is the most rapidly growing subgroup within the breast cancer family of diseases…[In the US], [m]ost new cases (more than 90%) are nonpalpable and discovered mammographically” (Silverstein, MacDonald, Mabry, and Moorthy in Winchester et al. 2006, p. 226). DCIS may or may not exhibit tumor necrosis. DCIS with necrosis has a greater chance of being an aggressive cancer. This type of DCIS may be called comedocarcinoma. Lobular carcinoma in situ or lobular neoplasia is a condition that is indicated in increasing a woman's risk of invasive breast cancer. It is not a "true cancer" but has been identified in some reports as a non-invasive breast cancer (ACS 2008).

Invasive or infiltrating ductal carcinoma (IDC) is the most frequent breast cancer. It originates in a breast duct and spreads beyond the duct into the fatty breast tissue. It may metastasize throughout the body using the lymphatic and circulatory systems. According to the ACS (2008), infiltrating ductal carcinomas represent eighty percent of invasive breast cancers. Invasive or infiltrating lobular carcinoma (ILC) begins in the lobules of the breast and can metastasize to other areas. Ten percent of invasive breast cancers are ILCs . In a mammogram, it may be harder to identify invasive lobular carcinoma than invasive ductal carcinoma (ACS 2008).

Inflammatory breast cancer is estimated to represent 1% to 3% of breast cancers. Inflammatory breast cancer may initially be misdiagnosed as mastitis due to its characteristic symptoms. Mastitis is "an infection of the breast tissue that causes pain, swelling and redness of the breast," and it "most commonly affects women who are breast-feeding" (Mayo Clinic 2008). The symptoms of inflammatory breast cancer are caused by “cancer cells blocking lymph vessels in the skin” (ACS 2008). The skin of the breast develops a red appearance, is warm to the touch, and has “a thick, pitted appearance…like an orange peel” (ACS 2008). The breast may also become “tender” or “itchy” (ACS 2008). A complicating factor in early diagnosis is that inflammatory breast cancer lacks a “defined lump,” so it may not be detected in screening mammograms (ACS 2008). Inflammatory breast cancer is more likely to spread than IDC or ILC, and the prognosis is also poorer. Other types of breast cancer include Paget disease of the nipple, mucinous (or colloid) carcinoma, tubular carcinoma, and medullary carcinoma (ACS 2008).

Breast cancers may also be classified in terms of hormone receptors. The term "triple-negative breast cancer" refers to breast cancers that lack estrogen and progesterone receptors and that also lack "an excess of HER2 protein on their surfaces." The lack of these receptors and the lack of "excess" HER2 protein limit potential treatments. Hormone therapy and drugs that "target" HER2 are not helpful in treating triple-negative breast cancers. Triple-negative breast cancers are most often invasive ductal carcinomas. Also, this type of cancer is more common in younger women and is likely to metastasize faster than most other breast cancers (ACS 2008).

4.4 Treatment

According to Wardley (Chen, Wardley, and Skarin 2007), "high-quality clinical research" has lead to better outcomes following a breast cancer diagnosis; "all aspects of breast cancer treatment have improved" (p. iv). Following diagnosis, healthcare professionals may employ a variety of techniques to determine the progression of the breast cancer. Additional mammograms, ultrasound, MRI, CT, PET scans, biopsies, bone scans, blood work, and other methods may be used to help determine the extent of the disease and the appropriate treatment options. Treatment methods depend on a variety of factors, including type of breast cancer, stage at diagnosis, age, co-morbidities, and personal preferences. The general treatment options available are surgery, hormone or endocrine therapy, chemotherapy, and radiation (radiotherapy). Treatment may also involve a combination of these options (ACS 2008; Hagen 2007).

If surgery is indicated, different types of procedures are available. Types of surgery include mastectomy, breast-conserving surgery, and axillary lymph node sampling and removal. The surgery may or may not involve removing the lymph nodes. Mastectomy is "the surgical removal of one or both breasts" Anderson, Keith, Novak, & Elliot 2002, p. 1055). Types of mastectomy include radical, modified radical, and simple mastectomy. A radical mastectomy is "the surgical removal of the entire breast; pectoral muscles; axially lymph nodes; and all fat, fascia, and adjacent tissues" (Anderson, Keith, Novak, & Elliot 2002, 1458). Following surgery, the patient may experience "edema of the arm" due to removal of the "axillary lymphatic structures that drain the lymph from the arm" and has a risk of "symptomatic

atelectasis" if breathing exercises are not used (p. 1458). Atelectasis is "the collapse of part or all of a lung" (Medline Plus 2008).

A modified radical mastectomy is "a surgical procedure in which a breast is completely removed with the underlying pectoralis minor and some of the adjacent lymph nodes. The pectoralis major is not excised. The operation is performed in treating early and well-localized malignant neoplasms of the breast. It appears to be as curative as the more extensive radical mastectomy when the tumor meets these criteria" (Anderson, Keith, Novak, & Elliot 2002, p. 1113). "In a modified radical mastectomy the large muscles of the chest that move the arm are preserved…The patient may be fitted with a prosthesis when the wound is completely healed or at the time of the mastectomy" (Anderson, Keith, Novak, & Elliot 2002, p. 1055).

Anderson, Keith, Novak, & Elliot 2002 describe a simple mastectomy as follows:

> "[the]breast is completely removed and the underlying muscles and adjacent lymph nodes are left intact. The procedure may be performed to remove small malignant neoplasms of the breast, or it may be done as a palliative measure to remove an ulcerated carcinoma in advanced breast cancer. It also may be done prophylactically when the patient has severe fibrocystic disease and a strong family history of breast cancer. Postoperatively, the process of recovery from a simple mastectomy is less uncomfortable and faster than that from a radical or modified radical mastectomy" (Anderson, Keith, Novak, & Elliot 2002, p. 1584).

A lumpectomy is the "surgical excision of a tumor without removing large amounts of surrounding tissue" (Anderson, Keith, Novak, & Elliot 2002, p. 1027). "Breast conservation therapy (BCT) with wide local excision (also called lumpectomy, tylectomy, or segmental mastectomy), followed by whole-breast irradiation, has become the more common method of treatment [compared to mastectomy (radical and modified)] for stage 1 and 2 breast cancer)" (p. 1027). "Numerous prospective and retrospective studies have shown the equivalence of mastectomy and breast cancer treatment with respect to disease-specific end points and the superiority of breast conservation with respect to quality of life measures" (Motwani and Strom in Winchester et al. 2006, p. 355).

As mentioned above, more conservative breast cancer surgery, such as lumpectomy, is becoming more common. In the past, total mastectomy was more common. Now, studies have demonstrated that total mastectomy does not significantly increase a woman's survival

rate (Hofvind, Sørum, & Thoresen, 2007). Also, Finkel (2005) reports that "A twenty-year follow-up of a randomized study comparing breast-conserving surgery with modified radical mastectomy for early breast cancer found the longer-term survival rate to be the same" (p. 43). "Total mastectomy has been replaced by breast conserving therapy (BCT) plus radiation for a significant majority of all patients with stage 0-II disease (Hagen 2007, p. 12). Also, SLN (Sentinel Lymph Node Biopsy) "was introduced in the 1990s. The SLN hypothesis is that the tumour initially drains to one or a few of the lymph nodes, and an axillary node dissection can be avoided if the sentinel lymph node(s) proves to be negative. The morbidity of a total axillary node dissection is well-documented, and correlates negatively with quality of life (Tasmuth et al. 1995 & 1996 and Hacet et al. 1999 as cited in Hagen 2007, p. 12). "SLN biopsy can be performed in most patients with T1-2N0 invasive cancers, DCIS [ductal carcinoma in situ], in addition to multicentric disease and after neoadjuvant chemotherapy" (Hagen 2007, p. 13). "Sentinel node biopsy has decreased the morbidity associated with the traditional axillary node dissection" (Hagen 2007, p. 23-24). Based on the current evidence, more conservative treatment and diagnostic methods not only appear to have no detriment on survival rate but may also contribute to improved quality of life for women following diagnosis and treatment.

Hormone therapy is an option for some patients. As Anderson, Keith, Novak, and Elliot (2002) note, "The presence of estrogen receptors in breast tumors is considered an indication for hormonal manipulation such as the administration of antiestrogens (Anderson, Keith, Novak, & Elliot 2002, p. 237). "Hormone-sensitive breast cancer can be effectively treated with agents that reduce the stimulation of tumor cells by estrogen" (Buzdar in Winchester et al. 2006, p. 331). Endocrine therapy treatment plans and strategies may vary based on whether the woman is postmenopausal or premenopausal (p. 332). Hormone therapies may function in the following ways: "blocking the receptors [for "hormone positive breast cancer cells]," "lowering the hormone levels," or by "eliminating receptors" (Finkel 2005, p. 49). According to Finkel (2005), about 60% of breast cancers are estrogen-receptor positive (p. 49). Tamoxifen (or Nolvadex), for example, is an anti-estrogen medication that is often used. However, side effects of tamoxifen and other hormone therapy medications may include "hot flashes," "headaches, fatigue, [and nausea]" (p. 50-51). Responses to medications and treatment will, of course, vary for each individual.

Following surgical treatment, a patient may receive adjuvant therapy to target potential cancer cells that survived the initial treatment process (ACS, 2008). According to Hennessy and Valero (in Winchester et al. 2006), "Historically, breast cancer relapse occurred in more than 70% of women undergoing radical breast surgery alone" (p. 312). Adjuvant systemic chemotherapy "reduces the risk of recurrence and death from breast cancer" (p.312). Rovere, Warren, and Benson (2006) note that "The fall in mortality from breast cancer in the face of rising incidence rates is testimony to the success of interventional strategies in the form of screening and adjuvant systemic therapies, which reduce the burden of micrometastatic foci and perturb the natural history of this enigmatic disease" (Rovere, Warren, & Benson, 2006, p. xi). Adjuvant chemotherapy "reduces such risks…through eradication of micrometastatic disease, which is not detectable with conventional radiological techniques at the time of diagnosis. Since the risk of having micrometastatic disease at diagnosis of breast cancer is dependent on the stage of disease, the absolute benefit of adjuvant systemic chemotherapy is related to tumor size and axillary lymph node status, in addition to other factors, such as the age of the patient, the tumor grade, and the hormone receptor" (p. 312). Though other definitions and delineations have been proposed, micrometastatic disease is a term that is usually used to describe "tumor deposits measuring less than 2 mm" (Quan 2004). Chemotherapy may be used to treat cancer, "control cancerous growth," or to ameliorate symptoms; Finkel notes that it may also be used to reduce the size of a tumor prior to surgical intervention (p. 47). Depending on the type of treatment, chemotherapy may have a wide range of side effects, including "hair loss, nausea, vomiting," and fatigue (p. 48).

According to Finkel (2005), radiation targets "a specific part of the body" while chemotherapy and hormones "act on the whole body" (p. 45). Finkel notes that treatment considerations include "patient characteristics such as age, ethnicity, tumor size, histologic type, hormone receptor status, and other biomarkers (measurable parameters in tissues, cells, or fluids" (p. 45). Radiation serves to "kill the cancer cells directly or shrink the size of the tumor with high-energy external beams" and "is most harmful to rapidly producing cancer cells and prevents these cells from reproducing" (p. 45). According to Finkel (2005), in some situations radiation may be the "only treatment needed" (p. 45). It may also be used to ameliorate breast cancer symptoms or to "slow the progression" of disease (p. 45). Radiation has demonstrated the ability to decrease the risk of local recurrence as well as to improve survival rates and the "disease-free survival rate after a follow-up time of twenty years" (p. 45). Brachytherapy in which "radioactive 'seeds' are implanted or delivered by catheter near

the tumor site" is also possible for certain early-stage breast cancers; this provides a more "targeted and localized delivery" of radiation (p. 46). Finkel (2005) notes the following potential side effects of radiation: "fatigue, skin redness, burns, and skin pain" (p. 47).

Some women also participate in clinical trials testing the effectiveness of newer treatment regimens. Breast cancer treatment may result in a variety of side effects and present a number of short-term and long-term risks. Surgery, chemotherapy, radiation, and hormone therapy all have advantages and disadvantages, and women in consultation with their healthcare providers choose a treatment plan based on their individual situations. Treatment may include a variety of components, such as both surgery and chemotherapy, depending on the stage and extent of disease.

4.5 Reconstruction, Follow-up, and Rehabilitation

Though reconstruction is not always an option, a woman may decide to undergo reconstructive surgery. This may be part of the initial surgery or may occur during the recovery process (ACS 2008). Some patients may choose to undergo immediate reconstruction (Fenner & Mustoe in Winchester, etc. 2006, p. 380). "Implantation of a prosthesis after mastectomy is optional and does not appear to decrease survival probability. Reconstructive surgery is also an option" (Anderson, Keith, Novak, & Elliot 2002, p. 237). According to Handel and Silverstein (2006), "As a result of the emphasis on preserving a normal-appearing breast, the role of the plastic surgeon in treating breast cancer patients has great expanded" (Handel and Silverstein in Winchester et al. 2006, p. 248). They further add that "In fact, the emergence of a new discipline, where the interests of the oncologic surgeon and the plastic surgeon overlap, has evolved into what is now labeled 'oncoplastic surgery.' This term refers to application of the principles and techniques of plastic surgery to the challenges of treating cancer patients…In individuals who require mastectomy, immediate breast reconstruction can be offered in nearly all cases" (Handel and Silverstein in Winchester et al. 2006, p. 248).

Breast cancer has not only physical effects but psychological effects as well. Finkel (2005) notes the existence of a "psycho-oncology" subspecialty (p. 162). Follow-up and rehabilitation focus on rebuilding the body as well as on helping women develop tools (and access resources) to cope with the psychological effects. While many women struggle with

physical effects, such as fatigue and lymphedema, following treatment for breast cancer, they may also struggle with the psychological effects of illness, body image issues, and considering the effect of illness on their families, marriages, careers, ability to bear children, and future aspirations. For some women, there may be the added burden of financial and economic concerns. The recovery process is very individual and can not be generalized. However, for some women, it may be important to find ways of "regaining a sense of control" and of dealing with the fear that the cancer may recur (Finkel 2005, p. 158-161). Others may prefer to find support within their existing networks of family, friends, colleagues, and organizations. A comprehensive program includes options for women to address both the physical and psychological effects of a breast cancer diagnosis and treatment. Options may, for example, include physical therapy, water aerobics, and self-help groups where women can have discussions with others who are undergoing (or have undergone) similar procedures. For women with young children, handling a breast cancer diagnosis and treatment comes at a time when they also have caregiving responsibilities (Kravdal 2003). Support groups and other resources may prove useful to some women. Appropriate information about rehabilitation options and appropriate access to rehabilitation resources can be important in the recovery process. Women must also work with their healthcare team to develop an appropriate plan for surveillance for future recurrence.

5. SOCIAL CAPITAL –IN GENERAL AND IN REGARD TO HEALTH OUTCOMES AND SCREENING

Studies, theories, and definitions of social capital have been under development for a number of years. Though a variety of definitions have been posited, social capital may be defined as "connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them" (Putnam 2000 as cited in Field 2008, p. 35). According to Field (2008), "[p]eople connect through a series of networks…to the extent that these networks constitute a resource, they may be seen as forming a kind of capital" (p. 1).

In more general terms, Field notes that "In economic thought, the term 'capital' originally meant an accumulated sum of money, which could be invested in the hope of a profitable return in the future" (p. 14). He traces the development of "the concept of physical capital, which was introduced to describe the role of machinery and buildings in increasing the productivity of economic activities" (p. 14). He notes that "in the 1960s…the idea of capital [was] stretched to cover people and their capacities"; according to Field, Theodore Schultz and later Becker "developed… the idea of human capital" (p. 14). Human capital was intended as "a tool to help economists measure the value of workers' skills"; according to Field (2008), Schultz and Becker believed that "labour…could be more or less productive…and it became more productive as a result of careful investment in, for example, education or healthcare" (p. 14). Capital was mostly concerned with "strictly economic terms"; "their [people's] value was measurable, their worth could be added up and compared, the relationship between input and outputs was a direct one, and any changes in value could be accounted for in terms of a common currency" (p. 14).

Field mentions that some have found it problematic to discuss "membership of networks" in terms of "capital" (p. 3). As Field himself notes, "Social contacts are not easily reduced to a simple set of common denominators" (p. 15). However, according to Field, the use of the term "capital" in this context "is related to the human capital tradition of thinking" and "similarly points to ideas of investment, accumulation and exploitation," such as have been used "in such areas as global development and anti-poverty strategies or the study of business innovation and technological change" (p. 4). The concept of human capital, which as

mentioned previously, "originally emerged in economics during the 1960s," "denotes the economic value to firms, individuals and the wider public of such attributes as skill, knowledge and good health" (p. 10). As previously mentioned in the "Existing Literature" section of Section 3, Grossman (Grossman 1999; Grossman in Culyer and Newhouse 2000) has described a human capital model in which he "views health as a durable capital stock that yields an output of healthy time" (Grossman in Culyer and Newhouse 2000, p. 348). He sets the parameters that "Individuals inherit an initial amount of this stock that depreciates with age and can be increased by investment" (p. 348). Social capital is an extension of a variety of concepts and models about capital.

The original idea of capital as "an accumulated sum of money" has now evolved into the modern-day concept of social capital. Field credits James Coleman "in his influential account of school performance in American cities" for "develop[ing] the concept of social capital as a way of integrating social theory with economic theory, claiming that social capital and human capital are generally complimentary" (p. 10). Field mentions that the World Bank and the Organisation for Economic Co-operation and Development (OECD) take a similar view; a European commission working paper even mentions "'the intrinsic link between human and social capital in the knowledge society'" (Field, p. 10-11). The OECD has suggested the existence of a "'strong complementarity' between human and social capital, with each feeding the other in mutually beneficial ways" (p. 10).

Another view, however, is that social capital is "an alternative to the concept of human capital, emphasizing the collective where the latter sees only individuals pursing their self-interests" (p. 11). Field finds more credence in the latter view, suggesting that "interest in social capital" may "represent…an attempt to modify the traditional focus of economics on individual behaviour, by stressing the social basis for people's decisions" (p. 11).

Field notes that interest in social capital has increased over time and that the concept has been used, discussed, and researched in a variety of areas and from a variety of perspectives. In particular, he mentions "a remarkable growth of interest in what might be called the micro level of individual behavior and experience" (p. 10). This includes studies of "intimacy and trust," which Field describes as "close to the heart of social capital" (p. 10). Social capital has been evaluated in regard to several different areas. In an examination of social capital effects from an economic perspective, for example, Glaeser, Laibson, and Sacerdote (2002)

mention that "social capital is higher among homeowners" and that it "rises in occupations with greater returns to social skills" (p. F437).

Field mentions that the concept that "bonds between people also serve as central building blocks of the larger social edifice" is not new. In 1916, Lyda Hanifan discussed "the contribution of 'goodwill, fellowship, mutual sympathy and social intercourse' to collective prosperity and well-being" (Hanifan as cited in Farr 2004 as cited in Field 2008, p. 15). Also, Émile Durkheim was "particularly interested in the way that people's social ties served as the thread from which a wider society wove itself together"; Durkheim says that "…the members [of society] are united by ties which extend deeper and far beyond the short moments during which the exchange is made" (Durkheim 1933 as cited in Field 2008, p. 13). This suggests that "social ties…contribut[e] to the wider functioning of the community" (Field 2008, p. 14). Field says that the "central idea of social capital is that social networks are a valuable asset" and that those networks "provide a basis for cohesion because they enable people to cooperate with one another – and not just with people they know directly – for mutual advantage" (p. 14).

Field notes that "[a]s well as being useful in its immediate context, this stock of capital can often be drawn on in other settings" (p. 1). Networks can stem from formal organizations, such as The League of Women Voters in the US, or be more informal, such as family and friendship connections. Field notes that "Modern organizations are governed by rules" and that therefore "Calling on trusted friends, family or acquaintances is much less stressful than dealing with bureaucracies, and it usually seems to work faster and often produces a better outcome" (p. 2-3). Field also notes that social capital and social networks do not always function in a positive manner. He mentions that "Social networks can sometimes serve to exclude and deny as well as include and enable" (p. 3). According to Field, "…people may sometimes find that options are constrained by the nature of the resources that they can get hold of through their connections"; however, "At other times, they will use their networks to liberate them from other constraints" (p. 3). Field posits that "At other times still, they will use their social capital to uphold their claims over those of others who are trying to access the same resources" (p. 3).

Field suggests that "People's networks should be seen…as part of the wider set of relationships and norms that allow people to pursue their goals, and also serve to bind society together" (p. 3). "Gary Fine has conceived of social movements as 'a bundle of narratives'

that commits participants to shared goals and identities" (Ericksen 2008, p. 207). The evolution of breast cancer organizations and programs is an excellent example. "Organizations to educate women about breast cancer started in the early twentieth century and focused on early detection" (p. 207). The American Cancer Society, for example, has a Tell a Friend program, "which has placed the burden of cancer detection on individuals and their social networks" (p. 209).

The concept of social capital has been approached from a variety of perspectives. According to Field (2008), for example, in the 1970s and 1980s, Pierre Bourdieu approached social capital in terms of "a concern with questions of unequal access to resources and the maintenance of power"; "eminent American sociologist" James Coleman, on the other hand, "takes as his starting point the idea of individuals acting rationally in pursuit of their own interests" (p. 23; p. 15). Bourdieu also noted that it was "insufficient" "to see capital solely in economic terms"; "both cultural capital and social capital should be treated as assets, representing the product of accumulated labour" (p. 18). Bourdieu also posited that "the notion of social capital was the 'sole means' of describing the 'principle of the social assets' which was visible where 'different individuals obtain a very unequal return on a more or less equivalent capital (economic or cultural) according to the extent to which they are able to mobilise by proxy the capital of a group (family, old pupils of elite schools, select club, nobility, etc.)" (Bourdieu 1980 as cited in Field 2008, p. 19). According to Field, Bourdieu felt that "social capital represented an 'aggregate of the actual or potential resources which are linked to possession of a durable network'" (Bourdieu 1980 as cited in Field 2008, p. 19).

In regard to "educational attainment," Coleman demonstrated that social capital "could…convey real benefits to poor and marginalised communities" (Field 2008, p. 23). He "concluded that communities were…a source of social capital that could offset some of the impact of social and economic disadvantage within the family (Coleman & Hoffer 1987 as cited in Field 2008, p. 26). Field mentions that "Unlike human and physical capital, which are normally a private good whose ownership and returns reside with individuals, Coleman portrayed social capital quintessentially as a public good that is created by and may benefit not just those whose efforts are required to realise it, but all who are part of a structure" (Coleman 1988-89 as cited by Field 2008, p. 26). Coleman suggested that "relationships are shown to constitute capital resources by helping to establish obligations and expectations between actors, building trustworthiness of the social environment, opening up channels of

information, and setting norms that endorse particular forms of behaviour while imposing sanctions on would-be free riders" (Coleman 1988-89 as cited in Field 2008, p. 27). Coleman felt that social capital was "'a capital asset for the individual'…built up of 'social structural resources'"; social capital was therefore "both individual and collective" (Coleman 1994 as cited in Field 2008, p. 28; Field 2008, p. 28). Coleman discussed the issue of whether or not social resources "could be called upon in practice" (p. 28). He felt this depended on "'the actual extent of obligations held' and 'the level of trustworthiness of the social environment'" (p. 28). These factors were "shaped by variations in social structures, including '…the general level of trustworthiness that leads obligations to be repaid, the actual needs that persons have for help, the existence of other sources of aid (such as government welfare agencies), the degree of affluence (which reduces the amount of aid needed from others), cultural differences in the tendency to lead aid and ask for aid, the degree of closure of social networks, [and] the logistics of social contacts'" (Coleman 1994 as cited in Field 2008, p. 28). Field says this might suggest that there were factors, "such as…a cultural propensity to request and offer aid," "favouring the development of social capital" and other factors, "such as affluence and welfare systems," "tending to undermine it" (Field, p. 28). If there are indeed factors that foster and cultivate the creation of social capital as well as factors that weaken its development, then it may be possible to positively affect screening participation by seeking to foster those factors or variables that contribute to the development of social capital. Field also noted that "Coleman's theoretical framework allowed for the possibility that some constructed forms of organization were more likely to promote social capital than others"; Coleman felt that churches were "particularly successful at promoting closure of networks" (p. 30).

Various definitions of social capital have been developed and used. Coleman "defined social capital as a useful resource available to an actor through his or her social relationships" (Field 2008, p. 26). Robert Putnam has been widely recognized for his contributions to research and discussion on social capital (Field 2008, p. 4). In contrast to Bourdieu and Coleman, Putnam has "inherited and developed the idea of association and civic activity as a basis of social integration and well-being" (p. 15). Field relates Putnam's assertion that the concept of social capital "was invented at least six times during the course of the twentieth century, each time to suggest that using connections to cooperate helped people to improve their lives" (p. 14). Field states that "Initially, the idea of describing social ties as a form of capital was simply a metaphor" (p. 14). This metaphor "implies that connections can be profitable; like any other

form of capital, you can invest in it, and you can expect a decent return on your investment" (p. 14).

Over time, Putnam has posited many definitions of social capital (Putnam in Field 2008). He has, for example, described it as "features of social organization, such as trust, norms, and networks that can improve the efficiency of society by facilitating coordinated actions" (Putnam 1993a as cited in Field 2008). Other definitions include "features of social life – networks, norms and trust—that enable participants to act more effectively to pursue shared objectives" and "features of social organisation…that can improve the efficiency of society by facilitating coordinated actions" (p. 35; p. 34). Putnam also described two types of social capital, bridging and bonding. Bridging social capital is "inclusive" and "tends to bring together people across diverse social divisions" while bonding social capital is "exclusive" and "tends to reinforce identities and maintain homogeneity" (p. 36). Bridging social capital is more useful for "'linkage to external assets and for information diffusion'" (p. 36). "Shared membership of secondary associations" may serve to "bring together individuals from quite distinctive and separate small groups" (p. 36).

In his book *Bowling Alone*, Putnam (2000) discusses the concept of social capital in great detail. While physical capital and human capital relate to "tools and training," such as "a screwdriver…or a college education," "that enhance individual productivity," social capital includes "social networks and the associated norms of reciprocity" and encompasses a variety of structures within society (p. 21). According to Putnam, this includes one's extended family, civic organizations, "the Internet chat group in which you participate," and one's "network of professional acquaintances" (p. 21). Putnam notes that the external effects of social capital are not necessarily positive. As previously noted, bridging is inclusive while bonding is exclusive. Putnam presents the US Civil Rights Movement as an example of *bridging* social capital while an ethnic fraternal organization would be an example of *bonding* social capital.

Some authors have discussed the effects of horizontal and vertical ties (Field 2008, p. 65-66). Horizontal ties are "those which create bonds between individuals in the same community or social group" while vertical ties are "between different groups up and down the social ladder" (p. 66). There is some evidence that vertical ties have a more pronounced effect on health than horizontal ties, which may have "few if any beneficial effects on health" (p. 66).

Woolcock (Woolcock 2001 in Field 2008) has proposed "linking" as a type of vertical social capital; this "consists of relationships up and down the social and economic scale" and "allows people to leverage resources, ideas and information from contacts outside their own social milieu" (p. 73). According to Field (2008), linking social capital may have special relevance for "community development policies" (p. 73).

Many studies have researched the relationships between social capital and various outcomes, such as criminal activity, achievement in educational settings, and health. In his work, Coleman concluded that social capital "could be an asset for disadvantaged social groups" (Field 2008, p. 32). Research has also shown a relationship between social networks and mortality rates; there were lower mortality rates among those with stronger social networks (p. 63). Studies of US data suggest that increased social capital "can enable better access to health care" (p. 64). Putnam has suggested four possible explanations for the relationship between social capital and health outcomes. Social networks provide "tangible material assistance, which in turn reduces stress" (Field 2008, p. 64). Also, social networks may "reinforce healthy norms" (p. 64). A third possible reason is that "the well-networked citizen may lobby more effectively for medical services" (p. 65). The fourth explanation suggested by Putnam is that social "interaction may actually help stimulate the body's immune system" (p. 65-66).

Studies have also researched the effects of social capital on well-being. According to Bornstein (Bornstein et al. 2003 in Field 2008), well-being is a "rather broad notion which includes mental health but also encompasses other positive aspects of human development such as life satisfaction" (p. 66). It should be noted that some researchers have questioned the legitimacy of generalizing individual level outcomes to "cover a whole population" (p. 67). Finding that social capital affects health and well-being on an individual level may not translate or extrapolate into the same findings on the population level. Overall, however, the "general pattern of the evidence at present does suggest a broadly positive relationship between social capital and health" (p. 67).

Durlauf and Fafchamps (2004) provides a comprehensive overview of social capital studies while Kawachi, Subramanian, & Kim (2008) provide an excellent overview of studies and the existing literature in regard to social capital and health. As previously mentioned, health inequalities and their causes have been examined from a variety of perspectives (Elstad

2000). Programs have targeted certain societal groups, such as women with lower income or immigrants, in attempts to increase screening rates. Less research appears to have focused on the outcomes of a breast cancer diagnosis and factors that influence treatment, rehabilitation, and recovery. In addition to emotional and physical issues that must be addressed by breast cancer survivors and their families, the economic loss may present an additional burden to patients and their families. There are many factors that may mitigate the potential negative effects of cancer diagnosis and treatment. Socioeconomic status, level of education, and access to appropriate treatment facilities have been identified as important factors. Though some research has used concepts of social capital to educate the community by making use of "lay health" advisors and existing community structures, such as churches and community organizations, the concept of social capital, however, has not been fully explored in relation to its effect on rehabilitation and the recovery process.

Studying individual characteristics may not be adequate to explain health outcomes and health behaviors. Studying "neighborhood context" may lead to a more informed analysis (Dailey et al. 2007). The literature indicates that social capital is an important factor in the utilization of healthcare services (Kronenfeld 2003). It also suggests that social capital and social participation impact a person's perception of whether or not she can influence her own health (Lindström 2006). A study by Kothari and Birch (2004) concludes that participation in social activities may mitigate the utilization effects on mammography screening of living in regions with "less educated" backgrounds. However, the literature also warns against using social capital as the only factor for predicting health service utilization rates (Kronenfeld 2003; Rosenberg et al. 2005). Though some articles mention a growth of social capital in the form of internet-based breast cancer support groups, many others document the loss of community connectedness and support.

The concept of social capital has been studied in regard to its impact on screening participation and on health outcomes. Some studies have suggested that social capital may ameliorate some of the effects of the "detrimental contributions of well-established biomedical risks" (Putnam 2000, p. 327). It is possible that social capital may have an effect on our health and on health consequences. This may function in many ways. For example, Putnam describes "tangible assistance," which might include money or transportation, as well as the function of social capital as a "physiological triggering mechanism" (p. 327). It is also possible that communities with high social capital "are best able to organize politically to

ensure first-rate medical services" (p. 327). Putnam mentions that studies have noted "the strong correlation between connectedness and health at the community level" (p. 327). Islam et al. (2006) found "a positive association (fixed effect)…between social capital and better health" while Folland (2006) predicts a change in risky behavior due to changes in social capital status, such as marrying or becoming a parent.

Lindstrom (2000) notes that "social participation is one important aspect of social capital as defined by Coleman and Putnam. This literature stresses the importance of inter-personal relations and trust, and social capital is thus partly a contextual trait….In conclusion, social participation is the psychosocial factor that is related to a number of health-related behaviors and to socioeconomic differences in these behaviors" (Lindstrom 2000). Lindstrom finds that "The higher the level of social participation in a neighborhood, the stronger the association between living alone, sick leave and unemployment, respectively, and low individual social participation" (Lindstrom 2000, p. 46). According to Lindstrom (2000), Berkman also found a relationship between social networks and health; "Social network and support factors may affect the health of a person by at least three different pathways" (Berkman et al. 1979 as cited in Lindstrom 2000, p. 48).

"More recently a range of authors have suggested that social capital might also be associated with positive health outcomes, and argued that Putnam's ideas might usefully be imported into the field of health promotion. If support could be found for this hypothesis, the implication would be that health promoters should put less energy into health education and the provision of information about health risks, and more energy into developing programmes and policies that enhance levels of social capital in low-health communities" (Campbell in Baron, Field, & Schuller 2002, p. 183). Studies examining the effects of social capital on health status have reached different conclusions; this may be due to differences in populations studied, research methods used, and how social capital is measured (Van Hooijdonk et al. 2008). Some studies have concluded that social capital does not have a "significant" effect on population health; Kennelly, O'Shea, and Garvey (2003), for example, found that "per capita income and the proportion of health expenditure financed by the government are both significantly and positively associated with better health outcomes" but found "little...evidence" that social capital has such an effect. They did find that social capital was related to better health outcomes. It should be noted that their study measured social capital using trust and "membership in voluntary associations" (p. 2367). Using data from the Oslo

Health Study 2000, Van der Wel (2007) found that when other variables, such as income and education were considered, social capital "is not associated with health"; he also concludes, however, that "place matters for health" (p. 71).

Other studies, however, have found links between social capital and health. Halpern (2005) notes that “Having more friends, going to church and taking part in voluntary associations…all have some positive impact on health”; he mentions that evidence for this statement is supported by “both cross-sectional and longitudinal research” (p. 87). A study in the Netherlands concluded that mortality from cancer was lower in neighborhoods with high social capital (Hoojidonk et al. 2008). However, as in regard to utilization rates of healthcare services, social capital alone may not be sufficient to explain health effects. Some research suggests “strong positive links between social capital and educational attainment, economic success, health and freedom from crime”; in these instances, however, social capital may be a contributing “factor” that works with other factors to create this effect (Field 2008, p. 69). Mohseni and Lindstrom (2007) find that "low trust in the health-care system is associated with poor self-rated health" (p. 1373). This may be related to "'not seeking health care when needed'" (p. 1373). This trust component may be important to consider in relation to social capital in that trust is considered by many authors to be an important part of social capital. Mohseni and Lindstrom (2007) describe trust in the healthcare system as "an institutional aspect of social capital" (p. 1373). Some studies suggest that "the beneficial properties of social capital can be found at the individual level"; Poortinga (2006) has findings indicating that social capital may not "uniformly benefit individuals living in the same community or society" (p. 292). However, in a study of Swedish data, Sundquist, Johansson, Yang, and Sundquist (2006) found that "individual health is affected by differences between neighbourhoods in linking social capital" (p. 954).

Islam et al. (2006) investigated the idea that social capital effects on health may vary in different countries. They reached the "tentative conclusion...that an association between social capital and health at the individual level is robust with respect to the degree of egalitarianism within a country" and that "Area level or contextual social capital may be less salient in egalitarian countries in explaining health differences across places." Folland (2007) has concluded that the hypothesis that social capital has an effect on population health is "on the whole...remarkably robust" but that there are situations in which the hypothesis "performs only weakly" (p. 2342). However, he clarifies that "it [social capital] distinguishes a clear

effect independent of the economic variables" (p. 2352). This point is particularly important because it addresses the possibility that social capital effects may actually be the result of socioeconomic variables. The conclusion that social capital indeed has its own effect on health is quite important. In this thesis, the effects of social capital are examined in conjunction with other variables and factors to determine the resulting effect on screening and health outcomes in the population surveyed.

There are many components that may contribute to the development of social capital. Coleman and Putnam, for example, felt that trust was an important part of social capital (Field 2008, p. 70). Trust may be a part of not only individual relationships but also of "an attribute of institutions and groups"; it may also be "based on reputation which is mediated through third parties" (p. 71). In regard to social capital, it has been suggested that different types and "dimensions of trust might represent varied ways of accessing resources" (p.71). Others feel it is better to view trust as an outcome of social capital rather than as a component of social capital itself (p. 72). This leads to an important issue. If social capital does indeed affect health outcomes and possibly screening issues, to design, implement, and evaluate programs, we must be able to in some way identify or quantify social capital.

Therefore, an important question and issue is how to measure social capital (Durlauf 2002). In fact, according to Field (2008), "Policy-makers who embrace the idea of promoting social capital are virtually unanimous in agreeing that measurement is the central challenge" (p. 142). Field mentions several countries that have attempted to measure social capital on a national level; these include Britain, Finland, and Australia (p. 143). The Policy Research Initiative (PRI) in Canada has studied the issue of measurement extensively and has "recommended indicators…based on network analysis methods, applied to the study of network structures and network dynamics"; important features include "the structural properties of networks," such as their size, "the characteristics of network members," such as "the extent of their diversity," and "their relational properties," such as "intensity and spatial proximity" (p. 143). Researchers and organizations, such as the OECD, have noted the importance of the cultural and local dimensions to the decision of how to measure social trust. The OECD has further suggested that trust may be used as "'an acceptable proxy [for social capital]…in the absence of a wider and more comprehensive set of indicators'" (p. 144). Field (2008) mentions results of a study from 1995 to 1996 in which Norway was found to be the OCED country "with the highest levels of trust" on the World Values Survey

(WVS) (p. 144-145). He is also quick to point out, however, that the results must be considered in light of other issues, such as the fact that the question about trust must be translated into other languages and that even locally "definitions of trust can vary" (p. 145). However, if, as some have argued, trust is more an outcome than a contributor to social capital, using trust as a proxy may be ill-advised (p. 145).

Field mentions that policy-makers are increasingly concerned about the "implications of social capital" (Field 2008, p. 146). Identifying ways of building social capital and measuring and "monitor[ing] the outcomes" is, however, a challenge (p. 146). The Forward Strategy Unit (FSU) in Britain suggested that "policy should be directed…with a particular focus on creating bridging social capital so as to transcend social, ethnic, religious and other divides" (p. 147-148). Fukuyama and others have described education as "a particularly direct means of investing in social capital" (p. 148). Field mentions a history of European governments using cooperation with voluntary organizations "as a way of delivering core services" (p. 149). There may be many benefits to considering social capital in the development of policies; a primary benefit may be that such policies "help improve the effectiveness of government, particularly in complex areas where many different arms of government have a potential interest in finding solutions" (p. 149). Another method to "promote" social capital may be "partner-based approaches"; in this method, communities are able to "actively" participate in "decision-making and programme implementation" (Field 2008, p. 150). This may serve as "a way of promoting sustainable changes in health, as well as tackling inequalities in health" (Davies 2001 in Field 2008, p. 150).

6. SOCIAL INEQUALITY

Though it will not be discussed in great detail within this thesis, it is also possible that screening participation in part reflects underlying social inequalities and socioeconomic differences in particular areas. The existence of a socioeconomic health gradient is, after all, well-documented (Ettner and Grzywacz 2003; Kravdal 2003; Daniels 2008). Ethner and Grzywacz (2003) note that "Health inequalities manifest as a gradient, rather than as a distinction between “"haves"” and “"have nots"” (p. 441). Worldwide, screening patterns have been linked to socioeconomic status, education, and immigrant status. In Norway, previous studies have found that participation in screening is related to trust, gratitude, and convenience (Østerlie et al. 2008). Screening behaviors may be linked to overall health. Therefore, it may also be pertinent to discuss the relationship between health and socioeconomic status. Within Norway, Dahl, Elstad, Hofoss, and Mollard (2006) found "the emergence of regional-level income inequality effects on mortality"; they note that "these effects were particularly marked among socioeconomically disadvantaged groups" (p. 2562). Internationally, numerous studies have researched the interactions between socioeconomic status and health. As Edmondson (2003) notes, social capital is "currently being discussed as a source of support for health" (p. 1723). Based on US data, Adams et al. (2003) examined links between health and socioeconomic status. They could not reach firm conclusions but did not rule out the possibility that "SES[socioeconomic status]-linked preventative care influences onset of chronic and mental diseases" (p. 3). They also mention previous studies "with the general finding that higher socioeconomic status (SES) is associated with better health and longer life" (p. 3). This effect has been documented for a wide variety of variables associated with socioeconomic status, including “wealth, education, occupation, income, [and] level of social integration” (p. 3).

Bolin, Lindgren, Lindstrom, and Nystedt (2003) investigate the interactions between social capital and health. Using a definition of social capital as "having a close friend outside the family," they predicted that "the amount of social capital is positively related to the level of health" (p. 2379). Based on data from Sweden, they conclude that "social capital is positively related to the level of health capital" and that "the level of social capital declines with age, is lower for those married or cohabiting, and is lower for men than for women" (p. 2379). They also mention previous studies that investigated the potential links between social

capital and health. Some researched has indicated an association between higher social capital and lower total mortality (p. 2379).

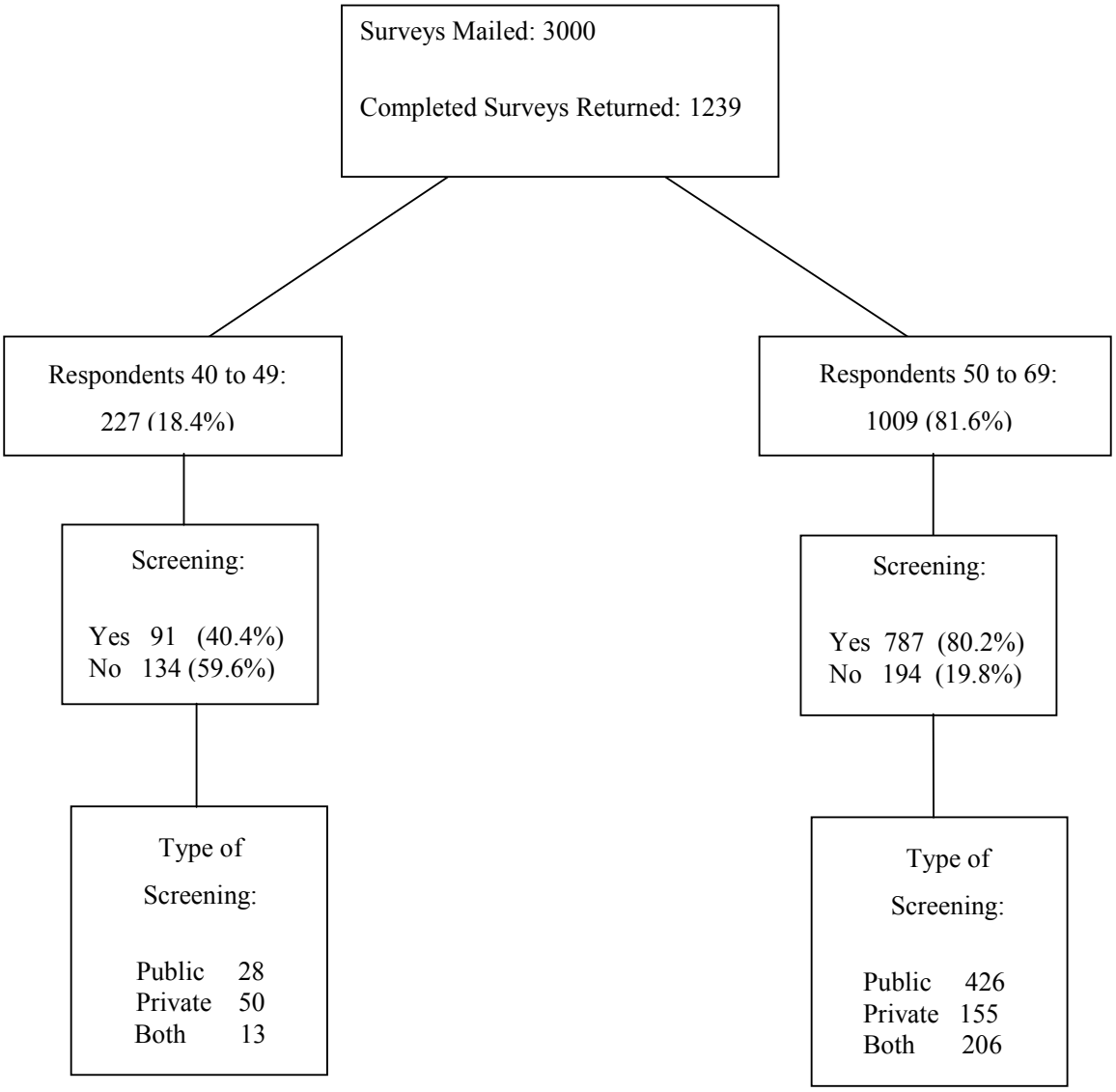
Though many studies have now recognized that social capital may have an effect on health and health outcomes, it is challenging to appropriately conceptualize, measure, and capture social capital and social capital effects. Harpham, Grant, & Thomas (2002), for example, discuss issues related to the measurement of social capital in health surveys, such as "cognitive, structural, bonding and bridging social capital." Harpham, Grant, and Thomas (2002) credit Bain and Hicks (1998) for the "disaggregat[ion]" of social capital into structural and cognitive components (Harpham, Grant, and Thomas 2002, p. 106). Harpham, Grant, and Thomas (2002) describe the two components as follows: "The Structural component includes extent and intensity of associational links or activity, and the cognitive component covers perceptions of support, reciprocity, sharing and trust. At the simplest level, these two components can be respectively characterized as what people 'do' and what people 'feel' in terms of social relations" (p.106). These concepts add additional dimensions to consider in evaluating or discussing social capital.

As Campbell and Gillies (2001) discuss, utilizing social capital and results of social capital studies to inform policy decisions and actually positively influence social capital itself requires further study. Baron, Field, and Schuller (2002) discuss the “potential role” of social capital in health education and public health (p. 185). Crothers (in McLean, Schultz, and Steger 2002) notes that attempts to “regenerate or reinvigorate social capital must be sensitive to the values, goals, and ideals of local populations” (p. 219). If we conclusively learn that social capital does have an effect on health and on screening, finding a way to utilize that information to positively influence health outcomes, well-being, and participating in screening will be a further challenge.

7. DATA

Data was collected using questionnaires sent to 3000 members of the *Foreningen for Brystkreftopererte*. By April 28, 2009, 1241 responses had been received. For various reasons, two respondents chose to opt out of completing the survey. The information and statistics that follow are based on the valid responses for the remaining 1239 returned surveys. If a respondent did not enter information for a particular question, such as year of birth or use of private screening methods, the statistics given are based on responses from those who did enter information for the relevant questions. Three respondents did not list their year of birth and are not included in the figure below. An overview of the valid responses received by April 28, 2009, is given below in Figure 2.

Figure 2. Questionnaire Responses



8. METHOD

Following the completion of a literature search, a questionnaire was developed in collaboration with Dr. Eline Aas, the *Foreningen for Brystkreftopererte,* and HERO, to elicit information about variables that may affect breast cancer screening, treatment, rehabilitation, and health outcomes. These variables included age, county, education, employment status, income, usage and frequency of public and private breast cancer screening options, and social capital factors, such as family relationships, friendships, and community and organizational involvement. Questions were also asked about the use of rehabilitation options and the usage of genetic testing. The questionnaire was sent to 3000 women aged 40 to 69 who are members of the Norwegian *Foreningen for Brystkreftopererte***.** The response rate was approximately 41.4%; 1241 questionnaires were returned. Of the returned questionnaires, 1239 had been completed.

Based on the literature review, several variables were identified that may be expected to have a positive influence on screening rates. Those variables are as follows: age, education, personal and household income, participation in the workforce, social capital as measured by household composition, number of friends, and participation in organization, and perceived risk as evidenced by prior genetic testing or willingness to take a genetic test. The following variables were expected to evidence a negative effect on screening rates: travel distance to public and private screening options and later introduction of public mammography screening to particular counties. The data was analyzed using SPSS 16 to investigate the hypotheses about the potential effects on screening and to determine which variables impacted breast cancer screening and the choice of screening options. Descriptive statistics cross tabulation, multinomial logistic regression, and ordinary least squares regression were utilized to identify the variables that impact screening and the choice of screening options. Due to sample limitations, an appropriate model could not be constructed to describe the probability that a woman will participate in screening. Descriptive statistics and an overview of trends and tendencies in the data are, however, provided in Section 9 “Results and Analysis.”

9. RESULTS AND ANALYSIS

Data analysis revealed some trends in mammography screening patterns. The probability of having participated in mammography screening appeared to be influenced by county of residence, age, education, and travel distance to screening.

9.1 Descriptive Statistics

A greater percentage of older women and women with university or college education had participated in screening. Women with university or college education also had a higher percentage of participation in private screening. Women 55 and older had a higher percentage of participation in both public and private screening. Also, a higher percentage of women with personal income of 400 000 NOK or higher (at the time of diagnosis) had participated in screening when compared to women with personal income of less than 400 000 NOK. A smaller percentage of residents in the following counties had been screened in comparison to the other counties: Finnmark, Nordland, Nord-Trøndelag, Telemark, Sogn og Fjordane, Vestfold, Hordaland, and Møre og Romsdal. More than one-third of respondents in Finnmark, Hordaland, Nordland, Nord-Trøndelag, Vestfold, and Telemark had not been screened prior to their breast cancer diagnosis. The screening percentage was approximately 66.7% for Sogn og Fjordane. A higher percentage of respondents had been screened in the following counties: Oslo, Akershus, and Vest-Agder. Approximately 85.7% of respondents from Vest-Agder had been screened prior to diagnosis while approximately 85.4% of Oslo County respondents had been screened. The screening percentages for each county based on valid survey data is listed in Table 10.

In regard to work, no real conclusions could be drawn. Older people were more likely to have been screened, but it is also possible that they are more likely to have entered retirement or screening ages, which affects the screening results for employed and unemployed respondents. Selected descriptive statistics are provided in Tables 3, 4, and 5. Women below the age of 50 are not generally part of the public mammography screening program. Therefore, selected separate descriptive statistics for the 40 to 49 age group and for the 50 and above age group are provided in Tables 6 through 9. A higher percentage of women in the 40 to 49 age group had taken a genetic test for breast cancer. However, there were fewer

respondents from the 40 to 49 age group. Within the 50 to 69 age group, women with an annual household income of 400 000 NOK were more likely to participate in private screening than women with household incomes of less than 400 000 NOK.

Table 3. Screening Status (N=1239)

Variable	**Screening Status**			
	Yes		No	
	Average	Standard Deviation	Average	Standard Deviation
Age	57.64	6.61	54.62	6.82
Travel Time (Public) (min)	37.57	37.42	39.71	37.62
Travel Time (Private) (min)	45.87	51.98	44.64	52.82
Household Income (NOK) (At Diagnosis)	743324	2.67×10^6	643663	6.48×10^5

Table 4. Variables Based on the Type of Screening Used By Those Screened (N=1239)

Variable	**Type of Screening**					
	Public Only		Private Only		Both Public and Private	
	Average	Standard Deviation	Average	Standard Deviation	Average	Standard Deviation
Age	58.72	5.97	54.24	6.72	59.18	5.73
Travel Time (Public) (min)	36.98	37.91	36.38	34.95	35.43	32.25
Travel Time (Private)	52.82	63.74	40.35	37.86	45.75	55.03
Household Income (NOK) (At Diagnosis)	625446	2.85×10^5	675041	2.88×10^5	719995	1.02×10^6

Table 5. Socioeconomic Variables Based on Screening Status (Percentages are not 100% for some variables due to missing or invalid responses for some questions) (N=1239)

Variable	**Category**	**Screening Status**	
		Yes	No
Age	Under 50 years old	40.1	59.0
	50 to 69 years old	78.0	19.2
Living Status (At Time of Diagnosis)	Alone	77.4	21.5
	With spouse or cohabitant	71.0	26.1
	Without spouse or cohabitant	60.9	39.1
	With someone aged 18 or older	67.9	30.1
	With someone under age 18	48.7	49.0
Income (Household) (At Time of Diagnosis)	Under 100,000 NOK	60.8	37.3
	100,000 – 199,999 NOK	67.8	30.3
	200,000 – 399,999 NOK	72.6	24.8
	400,000 – 599,999 NOK	74.0	24.9
	600,000 – 999,999 NOK	70.0	30.0
	1 million NOK or more	50.0	50.0
Education	Primary School	77.8	18.1
	High School	69.5	28.5
	University/College	68.8	29.6
Employment status (At time of diagnosis)	Employed (Yes)	69.8	27.6
	Not Employed (No)	77.1	21.5

*Table 6. Variables Based on the Type of Screening Used by 40 to 49 Age Group (N= 227 total respondents aged 40 to 49)**

Variable	Category	Type of Screening					
		Public Only		Private Only		Both Public and Private	
		Percent	Valid Responses	Percent	Valid Responses	Percent	Valid Responses
Education	Primary School	7.1	28	6.1	49	7.7	13
	High School	46.4		38.8		23.1	
	University/College	46.4		55.1		69.2	
Employment	Yes	78.6	28	90.0	50	92.3	13
	No	21.4		10.0		7.7	
Number of Good Friendships	None	0	27	2.0	50	0	13
	1-3	11.1		10.0		7.7	
	4-6	29.6		20.0		30.8	
	7-9	3.7		14.0		23.1	
	10 or more	55.6		54.0		38.5	
Genetic Testing for Breast Cancer	Yes	37.0	27	38.8	49	30.8	13
	No	37.0		22.4		38.5	
	No Offer	25.9		38.8		30.8	
Genetic Testing for Breast Cancer if Offered	Yes	85.7	28	71.4	49	84.6	13
	No	0.0		2.0		7.7	
	Do not know	14.3		26.5		7.7	
Living Status (Spouse or Cohabitant)	With Spouse or	87.5	24	87.8	49	84.6	13
	Without Spouse or Cohabitant	12.5		12.2		23.1	
Living Status (Persons Over Age 18)	Yes	20.0	20	28.6	42	25.0	12
	No	80.0		71.4		75.0	
Living Status (Persons Under Age 18)	Yes	75.0	24	83.0	47	83.3	12
	No	25.0		17.0		16.7	
Personal Income (NOK) (At Diagnosis)	Under 100,000 NOK	3.6	28	2.0	50	0	13
	100,000 – 199,999	14.3		12.0		7.7	
	200,000 – 399,999	50.0		58.0		53.8	
	400,000 – 599,999	28.6		24.0		30.8	
	600,000 – 999,999	3.6		4.0		7.7	
	1 million NOK or more	0		0		0	
Household Income (NOK) (At Diagnosis)	Under 100,000 NOK	4.2	24	0	46	0	10
	100,000 – 199,999	4.2		0		0	
	200,000 – 399,999	20.8		8.7		20.0	
	400,000 – 599,999	12.5		23.9		10.0	
	600,000 – 999,999	41.7		37.0		40.0	
	1 million NOK or more	16.7		30.4		30.0	

*Percentages are based on the entire group of respondents aged 40 to 49. Also, some respondents did not respond to every question. Therefore, in this and other tables, the percentages do not equal 100% in all cases.

Table 7. Variables Based on the Type of Screening Used by 50 to 69 Age Group (N=1009)

Variable	Category	Type of Screening					
		Public Only		Private Only		Both Public and Private	
		Percent	Valid*	Percent	Valid	Percent	Valid
Education	Primary School	32.5	525	16.8	155	25.9	205
	High School	27.1		34.8		29.8	
	University/College	39.5		48.4		42.9	
Employment	Yes	76.4	423	88.4	155	79.6	206
	No	23.6		11.6		20.4	
Number of Good Friendships	None	0.7	413	0	149	1.5	199
	1-3	11.9		12.1		11.6	
	4-6	28.6		37.6		29.1	
	7-9	13.8		11.4		11.6	
	10 or more	45.0		38.9		46.2	
Genetic Testing for Breast Cancer	Yes	15.7	389	21.6	148	14.4	187
	No	52.2		50.7		46.5	
	No Offer	32.1		27.7		39.0	
Genetic Testing for Breast Cancer if Offered	Yes	64.8	415	72.2	151	69.0	203
	No	14.5		9.3		8.4	
	Do not know	20.7		18.5		22.7	
Living Status (Spouse or Cohabitant)	With Spouse or Cohabitant	81.9	414	86.7	150	76.4	199
	Without Spouse or Cohabitant	18.1		13.3		23.6	
Living Status (Persons Over Age 18)	Yes	15.5	342	30.1	123	18.3	175
	No	84.5		69.9		81.7	
Living Status (Persons Under Age 18)	Yes	14.4	341	27.1	129	11.8	170
	No	85.6		72.9		88.2	
Personal Income (NOK) (At Diagnosis)	Under 100,000 NOK	3.9	412	4.0	151	3.4	204
	100,000 – 199,999	18.0		9.9		17.6	
	200,000 – 399,999	62.9		63.6		63.2	
	400,000 – 599,999	13.6		19.2		12.3	
	600,000 – 999,999	1.5		2.6		3.4	
	1 million NOK or more	0.2		0.7		0	
Household Income (NOK) (At Diagnosis)	Under 100,000 NOK	2.0	347	3.1	127	1.8	168
	100,000 – 199,999	2.6		0.8		2.4	
	200,000 – 399,999	20.5		9.4		21.4	
	400,000 – 599,999	24.5		27.6		20.2	
	600,000 – 999,999	40.6		47.2		40.5	
	1 million NOK or more	9.8		11.8		13.7	

**Number of Valid Responses*

Table 8. Total Number of Screenings for the 40 to 49 Age Group (N= 227)

Variable	Category	Total Number of Screenings							
		1 to 3		4 to 6		7 to 9		10 or more	
		Percent	Valid	Percent	Vali	Percent	Valid	Percent	Valid
Education	Primary School	9.1	5	7.4	2	7.1	1	0	0
	High School	45.5	25	37	10	28.6	4	27.3	3
	University/College	45.5	25	55.6	15	64.3	9	72.7	8
Employment	Yes	85.7	48	96.3	26	85.7	12	100	11
	No	14.3	8	3.7	1	14.3	2	0	0
Number of Good Friendships	None	1.8	1	0	0	0	0	0	0
	1-3	14.5	8	3.7	1	7.1	1	0	0
	4-6	23.6	13	37.0	10	35.7	5	27.3	3
	7-9	7.3	4	22.2	6	7.1	1	9.1	1
	10 or more	52.7	29	37.0	10	50.0	7	63.6	7
Genetic Testing for Breast Cancer	Yes	33.9	19	34.6	9	35.7	5	36.4	4
	No	30.4	17	26.9	7	42.9	6	36.4	4
	No offer	35.7	20	38.5	10	21.4	3	27.3	3
Genetic Testing for Breast Cancer if Offered	Yes	70.9	39	92.3	24	85.7	12	63.6	7
	No	1.8	1	0	0	0	0	9.1	1
	Do Not Know	27.3	15	7.7	2	14.3	2	27.3	3
Living Status (Spouse or Cohabitant)	With Spouse or Cohabitant	84.6	44	85.2	23	92.3	100	100	10
	Without Spouse or Cohabitant	15.4	8	14.8	4	7.7	0	0	0
Living Status (Persons Over Age 18)	Yes	26.7	12	25	6	10	33.3	33.3	3
	No	73.3	33	75	18	90	66.7	66.7	6
Living Status (Persons Under Age 18)	Yes	75.9	41	76	19	91.7	100	100	10
	No	24.1	13	24	6	8.3	0	0	0
Personal Income (NOK) (At Diagnosis)	Under 100,000	1.8	1	3.7	1	0	0	0	0
	100,000 – 199,999	12.5	7	14.8	4	14.3	18.2	18.2	2
	200,000 – 399,999	55.4	31	74.1	20	57.1	36.4	36.4	4
	400,000 – 599,999	26.8	15	7.4	2	21.4	36.4	36.4	4
	600,000 – 999,999	3.6	2	0	0	7.1	9.1	9.1	1
	1 million NOK or more	0	0	0	0	0	0	0	0
Household Income (NOK) (At Diagnosis)	Under 100,000	2.0	1	0	0	0	0	10	1
	100,000 – 199,999	2.0	1	0	0	0	0	0	0
	200,000 – 399,999	1.8	6	23.8	5	18.2	2	0	0
	400,000 – 599,999	17.6	9	9.5	2	18.2	2	10	1
	600,000 – 999,999	41.2	21	61.9	13	45.5	5	30	3
	1 million NOK or more	25.5	13	4.8	1	18.2	2	50	5

Table 9. Total Number of Screenings for the 50 to 69 Age Group (N=1009)

Variable	**Category**	**Total Number of Screenings**							
		1 to 3		4 to 6		7 to 9		10 or more	
		Percent	Valid	Percent	Valid	Percent	Valid	Percent	Valid
Education	Primary School	22.2	49	26.3	60	32.8	45	34.8	62
	High School	28.5	63	31.6	72	29.2	40	27.5	49
	University/College	49.3	109	42.1	96	17.8	50	37.6	67
Employment	Yes	85.9	189	79.1	18.2	79.9	111	79.8	142
	No	14.1	31	20.9	48	20.1	28	20.2	36
Number of Good Friendships	None	0.9	2	1.3	3	0	0	0.6	1
	1-3	12.5	27	13.1	30	10.4	14	11.1	19
	4-6	30.6	66	31.9	73	30.6	41	29.2	50
	7-9	13.0	28	11.8	27	17.9	24	9.4	16
	10 or more	43.1	93	41.9	96	41.0	55	49.7	85
Genetic Testing for Breast Cancer	Yes	15.8	32	14.7	31	21.7	28	19.9	32
	No	48.8	99	51.7	109	47.3	61	49.1	79
	No Offer	35.5	72	33.6	71	31.0	40	31.1	50
Genetic Testing for Breast Cancer if Offered	Yes	66.7	146	67.8	154	66.9	91	71.1	123
	No	10.5	23	10.6	24	11.0	15	15.0	26
	Do not know	22.8	50	21.6	49	22.1	30	13.9	24
Living Status (Spouse or Cohabitant)	With Spouse or Cohabitant	80.6	174	78.4	174	86.9	119	87.9	153
	Without Spouse or Cohabitant	19.4	42	21.6	48	13.1	18	12.1	21
Living Status (Persons Over Age 18)	Yes	27.0	48	17.7	34	16.1	18	17.8	26
	No	73	130	82.3	158	83.9	94	82.2	120
Living Status (Persons Under Age 18)	Yes	25.8	47	12.8	24	17	19	17	25
	No	74.2	135	87.2	163	83	93	83	122
Personal Income (NOK) (At Diagnosis)	Under 100,000	2.3	5	4.4	10	3.6	5	4.7	8
	100,000 – 199,999	13.2	29	15.9	36	18.1	25	18.6	32
	200,000 – 399,999	67.1	147	63.3	143	67.4	93	59.3	102
	400,000 – 599,999	14.2	31	14.2	43	9.4	13	14.5	25
	600,000 – 999,999	2.7	6	2.2	5	1.4	2	2.9	5
	1 million NOK or more	0.5	1	0	0	0	0	0	
Household Income (NOK) (At Diagnosis)	Under 100,000	1	2	2.1	4	1.7	2	2.9	4
	100,000 – 199,999	2.1	4	3.7	7	2.6	3	0	0
	200,000 – 399,999	15.2	29	19.4	37	12.9	15	17.3	24
	400,000 – 599,999	24.1	46	24.6	47	29.3	34	25.2	35
	600,000 – 999,999	48.7	93	41.4	79	42.2	49	41.7	58
	1 million NOK or more	8.9	17	8.9	17	11.2	13	12.8	18

Table 10. Screening Percentage By County (N= 1193 valid responses)

County	**Year Screening Was Introduced**	**Screening (%)**	**Valid Responses**
Akershus	1996	81.2	154
Aust-Agder	1999	75.0	12
Buskerud	2001	71.1	83
Finnmark	2000	40.0	15
Hedmark	2003	73.8	61
Hordaland	1996	65.9	85
Møre og Romsdal	2002	67.1	76
Nordland	2001	60.5	81
Nord-Trøndelag	2001	63.3	30
Oppland	2002	73.0	37
Oslo	1996	85.4	137
Rogaland	1995	75.3	77
Sogn og Fjordane	2003	66.7	18
Sør-Trøndelag	2001	73.8	61
Telemark	1999	65.4	26
Troms	2000	70.0	60
Vestfold	2004	66.2	80
Vest-Agder	1999	85.7	28
Østfold	2001	73.6	72

9.2 Limitations

As mentioned previously, there are numerous limitations to this study. The survey was distributed to women who have been diagnosed with breast cancer. This provides a far different sample than if it were randomly distributed to women in the general population of Norway. Also, the response rate by April 28 point was less than 50%. An additional difficulty is the possibility of selection bias in regard to age. Most of the responses were received from women aged 50 and older, which may further serve to skew the results of this analysis. Another consideration is survey design. Information about travel distance to public and private screening options was not obtained for all respondents or for most of the respondents who had not been screened prior to diagnosis. Therefore, it is possible that more information could have been gained about travel distance as a barrier to screening. It is also possible for respondents within the same county to have different travel distances to screening options or to make use of screening options in other counties.

Also, the way in which respondents understood the term "offentlig" mammography screening may have varied. Some respondents specified the frequency of "kontroll" healthcare visits in contrast with actually mammography visits, so it is possible that some respondents included "kontroll" visits in their total number of mammography screenings. Many respondents did not recall the year of their first mammography screening visit or the total number of times they had been screened. Also, some respondents included the screening visit in which they received their breast cancer diagnosis while others did not. Another complicating issue is that many respondents were not sure when they were first screened or of how many times they had been screened. When this information was not provided or an estimate was not given, it was difficult to include the respondents in the overall analysis of the use of screening options. The response set was smaller for some variables, and therefore creating an accurate model was problematic.

9.3 AVENUES FOR FURTHER ANALYSIS

Future analyses of a more complete data set of questionnaires could include a multinomial logistic regression to identify potentially significant variables in breast cancer screening. Various multinomial logistic regressions were performed in the analyses of the current data

set. However, as mentioned in the "Limitations" Section, there were limitations related to numerous missing variables, the small sample size and response set for some questions, and also possible selection bias problems in the current data set. Due to those limitations, presenting results and a model for predicting the probability of a woman attending public, private, or both types of breast cancer screening would be a bit premature and are not included in the Results section. However, if more surveys are received and with a more complete data set that is more representative and has a more complete response set, the results of such an analysis could prove quite useful.

With such a data set, an ordinary least squares regression comparing the total number of screenings in the 40 to 49 age group to the total number of screenings in the 50 to 69 age group could also be performed to assist in determining if there are any significant differences in screening among those who have access to public mammography screening and those who do not. Preliminary regression results suggest that there are significant differences. However, as previously mentioned, more data and responses are needed prior to presenting a valid result. Comparisons between these two age groups are of particular interest in Norway. While woman aged 50 and above are called in to public mammography screening in Norway, women below the age of 50 are not generally a part of routine public mammography screening. Descriptive statistics are provided for both age groups in the "Descriptive Statistics" section. However, the responses were predominately from the 50 and above age group. If a broader range of responses are received from the 50 and below age group or if a survey was performed that gathered more responses from the general population, analyses could be performed using the more complete and representative sample set.

10. CONCLUSIONS

As McGuire, Henderson, and Mooney (2005) state, "Screening for breast cancer may increase women's life-expectancy through detection and treatment of disease" (p. 84). It may also have positive effects on a woman's quality of life if it detects cancer in the earlier stages, thereby enabling more conservative treatment. Identifying variables that influence screening participation rates can assist in the development of policies and programs to target populations who are less likely to be screened. It is possible that learning more about social capital and other variables that influence the likelihood of a woman being screened for breast cancer may assist in developing programs or information that address potential barriers to screening. If we had learned, for example, that social capital does indeed affect a person's likelihood of participating in breast cancer screening in Norway, this may provide us with information on how to better present information about screening to segments of the population. It may also be possible that there are access issues that may need to be addressed. Identifying the relevant variables that influence screening participation can add useful information for the further development of the Norwegian Breast Cancer Screening Program.

In this paper, the effects of both formal and informal social capital were explored in conjunction with other more widely researched factors, such as socioeconomic status, on screening issues in the breast cancer screening population. More formal social capital, for example, may include participation in existing community organizations and social activities while informal social capital may consist of family relationships and friendships. In addition to examining the possible effects of social capital on screening, this thesis has also discussed the potential effects of social capital on health outcomes. Another topic involves utilization rates in Norway of public and private (opportunistic) screening options and the effects of these screening options. Access to relevant resources and the extent to which access is influenced by social capital as well as the issue of whether this leads to social inequality in screening and detection rates are also important issues. The analysis from the results of the questionnaire helps in the identification of important variables affecting screening rates. It also provides information on the effects of social capital and social inequalities on health outcomes.

The expectation was that higher social capital would be reflected in higher screening rates and perhaps also in the use of a wider variety of screening options. The effect, if any, of social capital on health outcomes was expected to be positive. Based on the current results, it can not be stated that social capital has evidenced a statistically significant or demonstrable effect on breast cancer screening or on the health outcomes of screening. The results have, however, identified other variables that influence participation in screening. This information may be useful in the development of policies and programs to increase screening uptake. Other sections of the survey may also prove useful for the development of programs to support women and improve their health outcomes following diagnosis. The questionnaire also tried to identify areas in which economic loss due to illness is not adequately mitigated, and the results from this should also prove quite useful in developing follow-up and support services for women during and after breast cancer treatment. It is not only important to increase screening rates. Providing adequate programming, support, and information to women during the treatment and rehabilitation stages is also vitally important.

Based on the analysis of the questionnaires, age, county, personal and household income, and travel distance to screening may have an effect on screening usage. Distance to types of screening options has also demonstrated an effect on which type of screening is used in particular counties. Also, as expected, income may also influence the use of private screening outcomes. Based on these results, it may be useful to increase the usage of the "Mammography Bus" and other options to increase screening in counties with longer travel distances to screening. Mammography screening has been evidenced to decrease mortality rates from breast cancer and to detect breast cancer in earlier stages of disease. Future studies may benefit from the refinement of the questionnaire used for this study and from the additional information gained about variables important to screening.

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